Health Policy and Research Foundation of California

CALIFORNIA'S WAR ON AIDS
California AIDS Prevention/Treatment Plan

April 2, 1987

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This document is presented in two sections each prefaced with a memorandum from the author.

I. Treatment - prepared by Rev. Albert Ogle

II. Prevention - prepared by Michael Gorman, Ph.D., M.P.H.

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SECTION I

TREATMENT

prepared by
Rev. Albert Ogle
Memorandum

To: Executive Evaluation Committee, Co-Chairs, and Observers

From: Rev. Albert Ogle, Project Consultant for Treatment

Date: April 2, 1987

Re: Draft Planning Document

Thank you for agreeing to review and comment on the attached Treatment Planning Document which is now in draft form. The structure of the document is as follows:

1. Establishing practical models of community based care.

2. Assessing existing services and unmet needs (various county plans and related documents for your information and interest are enclosed in this section).

3. Establishing goals and objectives for a 5 year AIDS plan for the State of California.

4. Highlighting policy issues and recommending policy reform to implement overall goals.

Section 5 is an overall summary of a health care continuum and estimated cost over 5 years. (this will not be available until next week).

I look forward to having your comments and further data by April 22. The home health care cost provisional data and URSA preliminary data on state wide service providers will be incorporated into the final plan.
I. Establishing Practical Models of Community Based Care Services.

Target Populations

The complex nature of this disease, particularly the difference between those individuals who qualify under the CDC's existing AIDS definition and those individuals who requiring HIV related treatment will continue to make our planning efforts provisional.

In establishing program goals for treatment of target populations we will use a recent CDC hierarchical definition for the populations who will be expected to utilize the programs outlined. The four stages are:

(1) Acute HIV Infection
(2) Asymptomatic or Latency Period
(3) Lymphadenopathy
(4) Symptomatic Infection

A. Program Goals for Stages 1 and 2 (HIV infected, asymptomatic individuals).

The goal of this component is to provide adequate education on transmission, self health care and provide access to available drug treatments while assisting the patient to make appropriate sexual health and attitude changes. The majority of patients in the target group will be employed and active and will need minimum medical intervention.

1. Confidential Testing of Blood

The demands on the Alternative/Confidential Testing Sites are increasing as various new populations require screening for HIV infection. These include heterosexuals, IV drug users, and ethnic minority populations. Some programs have been in operation for two years and have developed a highly professional important service to the community. These programs are now being duplicated in other areas. Basic and mandatory components of these programs should include:

(a) A Confidential information/appointment telephone service (in Spanish, where there is a significant Hispanic population).
(b) Pretest counselling utilizing videos, brochures and a trained public health nurse or licensed social worker.
(c) The confidential blood test.
(d) The disclosure of results at a post-test counselling session with either a public health nurse or licensed social worker.
(e) Referrals to an approved designated support/medical or psycho-social program.
1. Confidential Testing of Blood (cont.)

If the patient is seropositive - he/she should be encouraged:

(a) To visit a physician for a physical examination, preferably in the same facility, on the same day.
(b) To enter a HIV positive support group, STOP AIDS project, SHEP Project, IV drug abuse/HIV program with the next 36 hours.
(c) To receive immediate further information and counselling on HIV transmission and their health risk factors for themselves and others, and their legal rights.
(d) Risk reduction information should be available.

Patients who are seronegative should be:

(a) referred to a STOP AIDS, or SHEP type project or group which is developing decision making/values clarification skills in individuals who have been engaged in high risk activities.
(b) encouraged to make an appointment to return for testing in 6 months.
(c) given further education and information on HIV infection and risk reduction behaviors.

Confidential Testing Sites should be located in areas where there is a high prevalence of risk for HIV infection, particularly gay-identified communities, black and Hispanic communities and areas where there is significant IV drug use; family planning clinics, sexually transmitted disease clinics, and County health facilities. Local health officers should develop relationships with drug and alcohol abuse counselling and rehabilitation programs to make confidential testing available to patients at intake on a voluntary basis. Local physicians could freely utilize the existing laboratory facilities of the County to deal with an anticipated increase in the numbers of patients requesting the confidential test.

2. Medical, Psycho-social and Prevention Standards for HIV Infection in Stages 1 and 2.

A patient is referred by the Confidential Testing site or another physician to an identified HIV-treatment center. Here a physician will perform a complete medical examination with medical and sexual history. The physician will ask for informed consent to inform designated people of the patient's seropositive status. These designated people will constitute the patient's health management team; e.g., the physician, nurse, social worker, and others as necessary. It is anticipated that all seropositive individuals will require information and access to clinical drug trials. We should assume this access to be ethically important and necessary in the overall health management of the patient. Access to this
2. Medical, Psycho-social and Prevention Standards for HIV Infection in Stages 1 and 2 (cont.).

Information could be available through a computerized drug treatment information system which would be made available to designated AIDS service providers throughout the State. These would be updated and centralized through the University of California Clinical drug trials programs and input from the Computerized AIDS Information Network or the proposed AIDS clearinghouse.

There are an estimated 250,000 HIV infected individuals in California. The drug Ribavirin under clinical trials has shown to be useful in delaying the onslaught of more serious diseases associated with HIV infection. The cost of providing this drug to a patient is approximately $4,000 per year. Under revised Medi-Cal regulations, this or another drug could be made available to people with HIV infection. Although many of these individuals will continue to work, private insurance will probably not be able to cover the cost of treatment because of confidentiality issues. If insurance companies were not permitted to refuse insurance coverage to someone who is seropositive, private insurance for the cost could be used.

The benefit of this health maintenance program would be:

(a) providing incentives to populations at risk to voluntarily be tested and to utilize medical, educational, and psycho-social programs to reduce transmission of the disease and to prevent people from progressing to HIV stages 3 and 4.
(b) self identified population at risk for AIDS would be offered incentives to seek treatment and alter high risk behaviors.
(c) improved surveillance and epidemiologic data.
(d) lowering the long term cost of health care.

3. IV Drug Users in HIV Stages 1 and 2 and Involving Physicians

It will be important to provide immediate access to HIV testing for IV drug users when they enter the counseling, detox, prison or social services system. One problem illustrated at the Santa Cruz site visit was the important opportunity of giving AIDS education and confidential blood testing simultaneously when someone enters a drug counselling or rehabilitation program. If this opportunity is delayed through waiting several weeks for an appointment or going to another site for testing, often the patient will not have the same urgency or desire to be tested. Confidential blood testing should be available at these sites with special pre and post test counselling training for alcohol and drug abuse personnel.
3. IV Drug Users in HIV Stages 1 and 2 and Involving Physicians (cont.).

Arrangements could be made with local county health officers to utilize county laboratories for blood testing. This could also be made available to physicians in counties where there is a scattered rural community and where the Anonymous Test Site was some distance away (as in Santa Cruz), or where local physicians in urban areas were willing to be involved in this public health strategy with individuals who thought they might be at risk for infection. Those infected individuals could be referred to the various treatment and counseling centers by the physician.

4. HIV infected children, hemophiliacs, and prison detention populations.

Special programs will need to be created for asymptomatic patients in these categories utilizing the principles in the proceeding section. Special mental health programs will need to be developed for patients and siblings of infected children and hemophiliacs, infected prisoners who will need special counselling and risk reduction programs.

B. Program Goals for Stages 3 and 4 (lymphadenopathy and symptomatic infection): The Development of Regionally Based AIDS Treatment Centers

For the purposes of the planning process we will estimate a ratio of 1:1 AIDS/severe ARC in need of treatment (See CDC memo December 31, 1986, following this page)

In developing a long range strategy for dealing with these projected numbers, it will be necessary to designate particular centers where AIDS treatment and care is available. This will be best achieved through developing a regional approach to planning, resource allocation, data collection and management. The existing regional system of Sexually Transmitted Disease areas currently utilized by the California Department of Health Services' Office of AIDS, does not reflect current service providers networks or patients needs. Patients outside of San Francisco and Los Angeles are often drawn to the larger metropolitan service providers because of lack of local services or skill in dealing with AIDS. In all five site visits, there is clear emerging inter-county cooperation and willingness to explore new inter-county AIDS initiatives. In Santa Cruz for example, the emerging problem of IV drug users with AIDS over the next 2-5 years would require special methadone/detox and rehabilitation programs for people with AIDS. The County did not expect to have the numbers (50) of patients it would take to open a cost efficient program on its own, but could with the support of local counties. Precedent has already been established through a Hispanic women's rehabilitation program, "Hermenos 10" in
Donald O. Lyman, M.D.
Office of AIDS
1812 14th Street, Room 200
P.O. Box 160146
Sacramento, California 95816-0146

Dear Dr. Lyman:

As you requested, I have modelled the trends in AIDS case reporting for the State of California. The analysis are based on cases reported to the CDC as of December 29, 1986 and uses the methods described in the statistical report you received earlier. Table 1 (attached) gives reported cases (by date of diagnosis) and deaths (by date of death) for the years 1981-1986, along with projections for the years 1986-1991. Projections for 1986 are included since the numbers are still incomplete due to reporting delays. The model indicates that a cumulative total of nearly 50,000 cases of AIDS will be diagnosed among California residents by the end of 1991, with roughly 34,000 deaths.

The distribution of diagnosed cases by geographic area appears to be shifting somewhat (Table 2). A smaller proportion of cases are being reported from San Francisco and a larger proportion reported from areas outside of San Francisco and Los Angeles. If present trends continue, an estimated 31% of cases diagnosed in 1991 will be from these other areas. This is similar to trends seen elsewhere in the country. Larger percentages of the cases are being reported from areas outside of those in which AIDS was first diagnosed.

I need to stress that all of these projections are empirical and based solely upon past trends in reporting. The confidence bounds given in the tables are derived under the assumption that the empirical models are correct; as such they should be considered to overestimate our true confidence. The effects of changes in behavior, such as the use of safe sex, will be modelled only so far as these changes have become manifest in current AIDS case reporting. The projected number of deaths are based upon past experience. It remains to be seen what effect new treatments such as AZT will have.

I hope you find this information helpful. If you have any questions, please let me know.

Sincerely,

W. Meade Morgan, Ph.D.
Statistics and Data Management Branch
AIDS Program
Centers for Disease Control

Enclosure
Table 1
Reported Cases of AIDS and AIDS-Related Deaths among Residents of California - December 29, 1986

<table>
<thead>
<tr>
<th>Year</th>
<th>Cases Diagnosed</th>
<th>Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>1981 &amp; before</td>
<td>67</td>
<td>21</td>
</tr>
<tr>
<td>1982</td>
<td>202</td>
<td>66</td>
</tr>
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<td>1983</td>
<td>639</td>
<td>253</td>
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<td>1985</td>
<td>2136</td>
<td>1136</td>
</tr>
<tr>
<td>1986</td>
<td>2129</td>
<td>1122</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Year</th>
<th>Cases Diagnosed (68% bounds)</th>
<th>Deaths (Range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1986</td>
<td>3250 (3100, 3400)</td>
<td>1930 (1870, 2000)</td>
</tr>
<tr>
<td>1987</td>
<td>4650 (4350, 4950)</td>
<td>2950 (2800, 3100)</td>
</tr>
<tr>
<td>1988</td>
<td>6300 (5600, 6900)</td>
<td>4200 (3900, 4500)</td>
</tr>
<tr>
<td>1989</td>
<td>8200 (6600, 9300)</td>
<td>5700 (5000, 6300)</td>
</tr>
<tr>
<td>1990</td>
<td>10400 (7500, 12100)</td>
<td>7500 (6050, 8500)</td>
</tr>
<tr>
<td>1991</td>
<td>12900 (8100, 14600)</td>
<td>9600 (6950, 11150)</td>
</tr>
</tbody>
</table>

Table 2
Percent of California Cases by Area (SMSA) of Residence December 29, 1986

<table>
<thead>
<tr>
<th>Year</th>
<th>San Francisco</th>
<th>Los Angeles</th>
<th>Other California</th>
</tr>
</thead>
<tbody>
<tr>
<td>1981 &amp; before</td>
<td>52.2</td>
<td>32.8</td>
<td>14.9</td>
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<tr>
<td>1982</td>
<td>53.0</td>
<td>35.6</td>
<td>11.4</td>
</tr>
<tr>
<td>1983</td>
<td>48.0</td>
<td>39.3</td>
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<td>1984</td>
<td>48.6</td>
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<td>1985</td>
<td>42.6</td>
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</tr>
<tr>
<td>1986</td>
<td>45.1</td>
<td>37.2</td>
<td>17.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Year</th>
<th>San Francisco</th>
<th>Los Angeles</th>
<th>Other California</th>
</tr>
</thead>
<tbody>
<tr>
<td>1986</td>
<td>42.8</td>
<td>37.3</td>
<td>19.9</td>
</tr>
<tr>
<td>1991</td>
<td>33.5 (29.4, 37.7)*</td>
<td>35.7 (31.4, 40.1)*</td>
<td>30.8 (26.4, 35.5)*</td>
</tr>
</tbody>
</table>

*68% confidence bounds are given in parentheses.
B. Program Goals for Stages 3 and 4 (lymphadenopathy and symptomatic infection): The Development of AIDS Regionally Based Treatment Centers (cont.).

Watsonville which is serving Santa Clara, Santa Cruz and San Benito counties, funded from a Federal block grant.

In Orange County where some AIDS patients are served in Los Angeles, the local health officer is establishing networks between the neighboring counties of Los Angeles, San Bernadino, Ventura, and Riverside to solve problems and collect data and possibly establish services.

In the Bay area, the Health Officers Association of California (HOAC) has developed a preliminary proposal to establish a nine county regional AIDS district (enclosed) to improve cooperation between the counties, their services, and their data collection.

People with AIDS and service providers in El Dorado County, are served by the Sacramento AIDS Foundation and rely on UC Davis or Mercy Hospital in Sacramento for specific medical treatment. The Sacramento area is already developing AIDS education in a nine county region and some of the volunteers of the Sacramento AIDS Foundation live in these counties, serving local patients. Placerville and South Lake Tahoe have been developing small scale inpatient and outpatient care, with one HIV infected individual in a local convalescent facility.

We recommended the Office of AIDS develop a regional configuration of counties and health districts for AIDS services based on the existing vital networks of service providers and patients needs.

Once established, the regions should develop their own AIDS Treatment Centers based at hospital facilities where the following program goals are utilized. Contracts to establish these centers could be awarded on a competitive basis to hospitals within each region. As part of a statewide comprehensive AIDS program, each hospital would be required to develop standards of care applicable to its specific AIDS population in accordance with the program standards and administrative requirements articulated in all State and Federal codes. Each contractor would not only develop a methodology for determining that individual institutions are meeting stated objectives, but would eventually develop a set of uniform and generic standards based on the experiences of the AIDS Treatment Centers. It is assumed the hospital would develop new and innovative links with community programs through subcontracting or entering into contracts as joint ventures with existent AIDS service providers. The overall goal of this program would be to establish a comprehensive case management system for people with HIV stages 3 and 4, permitting patients to maintain the quality of their lives in home environments as long as possible.
B. Program Goals for Stages 3 and 4 (lymphadenopathy and symptomatic infection): The Development of AIDS Regionally Based Treatment Centers (cont.).

The Centers would provide for all levels of care and services required by the AIDS patient including:

- Ambulatory and inpatient care
- Home health and attendant care
- Psycho-social and spiritual services
- Psychiatric and treatment and care services for dementia
- Hospice, death, dying and bereavement services
- A continuum of residential services
- Skilled nursing facilities
- Legal, financial and social services related counseling
- Clinical drug therapy and information and access to experimental treatment programs
- Occupational therapy
- Volunteer recruitment, training and support services
- Physician or other appropriate referral.

This comprehensive responsibility for a wide range of health and non-health services will be implemented through a case management model. The centers would be responsible for development and management of a comprehensive case management plan reflecting a complete continuum of direct services by the institution and community services. A multi-disciplinary team would be responsible for all aspects of a patients in hospital and post hospital needs with a specific case manager assigned responsibility for coordinating the service needs of each patient. A patient management plan would be developed ensuring that specific service needs were identified.

1. Integrated and comprehensive services will be provided at site to include as a minimum the following:

A designated patient care unit for AIDS patients, or another plan other than a designated unit, if the AIDS Treatment Center meets all other requirements of this section and the hospital can demonstrate:

(a) that is unable, due to structural or space limitations, to place the AIDS patients in a designated unit; or

(b) specific programmatic or operational reasons why it is preferable not to use a designated unit or not practicable to have a designated unit for AIDS patients.

The author views a discrete unit as a highly desirable concentration of hospital resources so as to enhance patient care. It is not expected that all patients will be
1. (cont.)

- treated within the discrete unit, intensive care unit (ICU) care being one exception and with exceptions for other specialized services or patients. In addition, census peaks may occasionally be expected to require treatment in other units.

2. **Ambulatory or outpatient services for screening, diagnostic and treatment services specifically for AIDS patients.**

   The emphasis of designated AIDS Treatment Centers should be on outpatient services with discrete acute care unit backup. It is expected that ambulatory care services will be provided through a combination of the hospital's own outpatient clinics and services or in an organized setting. At its core, the center should provide primary ambulatory care services to AIDS patients, outpatient clinics or walk-in clinics capable of identifying suspected AIDS cases operating in conjunction with oncology clinics or infectious disease services, which can provide outpatient participation in chemotherapy and clinical drug trials. Dental services for patients in this category should also be provided.

3. **Emergency services, available 24 hours a day, for treatment of AIDS patients.**

   The emergency services of the AIDS treatment center should have the capability to link a suspected AIDS patient with the center's program of comprehensive services and to provide a known AIDS patient with appropriate continuity of care. Emergency room staff should be trained in the center's protocols specific to the needs of AIDS patients.

4. **Other health care services, as appropriate, are provided directly or through contract for AIDS patients, to include at least the following:**

   (a) Home health care provided through a home health care agency licensed or certified under state regulations made available 24 hours a day, 7 days a week; and

   (b) Personal care.

   The AIDS Treatment Center should provide or arrange for the provision of the full range of home health services, including nursing, nutrition, home health aide services, occupational therapy, dentistry, speech therapy and social services. Personal care services by home attendants should be provided or arranged as necessary and appropriate. Home health care services should have the capability to address the specific needs of each of the various high risk groups affected by AIDS using as a base the existing protocols for delivery of home health services for patients with communicable diseases and terminal illnesses. AIDS
4. (cont.)

Treatment Centers in California should work closely with the California Department of Health Services for home health care and personal services as needed by the patient population.

5. The following programs and services are required to meet the needs of AIDS patients in this category:

(a) Residential health care: through Skilled Nursing Facilities, Board and Care Facilities, and other programs.
(b) Residential hospice services, including death dying and bereavement counselling; the San Francisco "Coming Home" model may be useful (enclosed in the Policy Recommendations section).
(c) Residential programs based on the San Francisco Shanti model,
(d) Shared housing programs based on the San Jose Catholic Social Services model (enclosed in the Santa Cruz site report section 2).
(e) Respite care for significant caregivers of an AIDS patient.
(f) Adult day care facilities.

As necessary and appropriate to the needs of AIDS patients, the AIDS Treatment Center shall provide or arrange for residential health care, hospital and residential living programs or shared housing arrangements. It is recognized that sufficient housing capacity, hospice services or residential health care services may not be readily available; however, the case management team or individual case manager must make reasonable efforts to seek out additional health care and community resources for AIDS patients needs and levels of care. This component could be subcontracted to many of the AIDS organizations, religious institutions or housing programs already involved in service provision.

6. Diagnostic and therapeutic radiology services and other specialized services are made available to meet the needs of AIDS patients.

The AIDS Treatment Center shall provide or through transfer agreements with other hospitals make available to AIDS patients specialized diagnostic and therapeutic services, for example radiology services and dialysis services, as needed and appropriate.

7. Inservice education programs which address the medical, psychological and social needs specific to AIDS patients are conducted for all hospital personnel caring for AIDS inpatients.
7. (cont.)
The AIDS treatment center shall develop and provide inservice education programs for all personnel caring for AIDS patients to ensure that staff are sensitive to and prepared to meet the needs and problems of groups affected by AIDS. Inservice education programs should also address the stress management and social support needs of hospital and other staff caring for AIDS patients.

8. Infection control policies and procedures specific to AIDS are developed and implemented as an integral part of the hospital wide infection control program. CDC recommendations concerning infection control guidelines, based on currently available scientific and medical evidence about AIDS and its transmissibility, should be adapted and integrated with the hospital-wide infection control program.

9. A quality assurance program which includes a review of the appropriateness of care of patients with AIDS is developed and implemented as an integral part of the overall quality assurance program.

The AIDS Treatment Center should provide specific assurance and control over the quality of care provided to each AIDS patients through the comprehensive patient management plan. Specific quality assurance of the overall hospital quality assurance program.

10. At the request of the Department of Health Services, the AIDS Treatment Center participates in clinical research programs approved by the hospital's Institutional Review Board.

(a) The AIDS treatment center will provide training to physicians on AIDS and clinical studies and assist with administrative work associated with patients on drug trials (The Sherman Oaks Outpatient Clinic in Los Angeles has a good physician based model program for administering clinical drug trials).

(b) The center should provide information to the public on research and drug studies and how patients can accept their services.

Since there is no known treatment for AIDS and much basic and clinical research is underway concerning the etiology, course and treatment of AIDS, it is essential that the AIDS Treatment Center be linked with and knowledgeable of state-of-the-art clinical treatments and therapies and work closely with the small percentage of physicians who are treating the majority of AIDS patients, many of whom will be involved more closely with clinical drug trials.
11. A crisis intervention program is made available in coordination with other existing community services.

This program should incorporate peer and professional counseling for people with AIDS (and their loved ones, people with dementia, alcohol and drug abusers with AIDS,) with psychiatric services. This should also include bereavement counseling to significant others of the deceased.

The AIDS Treatment Center is expected to provide crisis intervention, counseling and partial services either directly or by arrangement for service, with community based agencies to AIDS patients being managed by the center and to suspected AIDS patients and the families or other individuals with significant personal ties to AIDS patients. Programs for people with dementia, alcohol and drug abusers with AIDS, will require residential programs which would probably be subcontracted.

12. The AIDS Treatment Center is required to ensure that each AIDS patient has a case management plan which specifically addresses the patient's care needs. The case management plan should be accomplished through the following program elements which are based on the Blue Shield of California model.

(a) Case management defined

Although Case Management as a formalized program is fairly new, most of the concepts underlying this approach to benefit management have a long history at Blue Shield. A part of the Cost Containment Program, Case Management focuses on the early identification of long-term, high-cost treatment without compromising in quality of care. With the patient's interest uppermost in mind, we locate programs and manage health care benefits for subscribers and dependents as cost effectively as possible.

(b) Case management concepts

(i) Case management promotes the use of less costly care within the framework of normal contract benefits.

For example, transfer from an acute care facility to a skilled nursing facility may be encouraged in appropriate cases. While both types of facilities may be covered by contract benefits, the nursing facility provides the necessary level of care at a substantially lower cost.

(ii) Case management may also facilitate the provision of extra-contractual benefits when such coverage meets patient needs while reducing overall benefit costs.
(ii). (cont.)

For example, Blue Shield might approve payment for construction of a wheelchair ramp in a patient's home, or rental of an apartment in proximity to needed outpatient treatment facilities. While neither of these is a plan benefit, such costs may be allowed when necessary to meet the patient's health needs at a lower cost than would be possible in the hospital setting.

(iii) Case management is possible only when supported by the patient, family and attending physician.

While the program is entirely voluntary, the benefits of case management are both obvious and substantial:

(i) Quality of care is not compromised and indeed may be enhanced, especially as concerns the patient's emotional well being.

(ii) Care is provided in the most cost-effective setting.

(iii) Transfer of the patient to a less intensive treatment environment occurs in a timely and carefully planned fashion.

(iv) Benefits that are not otherwise available may be provided to cover unusual expenses of an alternative care program.

c. How case management works

Since early detection of cases is essential to effective cost containment, a comprehensive program of case identification has been developed at Blue Shield. Cases are identified by monitoring:

(i) Diagnoses (see partial list below)

(ii) Lengths of stay (20 days or more for adult patients; 10 or more for newborn and pediatric patients).

(iii) High-cost stays (cases in which charges exceed $30,000 within 14 days, or $50,000 for adults and $30,000 for children)

(iv) Repeated hospitalizations (same patient within eight months)
Commonly monitored diagnoses include:

Cerebral vascular accident (CVA)
High-risk neonates (newborns) - babies born with deformities or body systems that do not function normally
Severe head trauma (injuries)
Spinal cord trauma and infections
Coma from any cause
AIDS (Acquired Immune Deficiency Syndrome)
Respiratory conditions that require ventilator assistance
Amputation of limbs
Multiple fractures
Burns from any cause

Potential cases are identified at Blue Shield through:

Pre-Admission Review
Marketing
Professional Relations and Hospital Relations
Medical Review Administration (MRAD)
Customer Service
Claims Processing

Outside contacts may include:

Attending physicians
Hospital discharge planners
The subscriber or family members
Employers and brokers
Nurses, social workers, clergy, etc.

After a case is identified, it is referred to the Blue Shield Case Management Coordinator for review of patient eligibility and available contract benefits, and for consultation with the attending physician, hospital discharge planners and the patient or responsible family member.

Concern addressed by this review include:

Availability of necessary community health resources
Suitability of home or other living arrangements
Personal and family considerations
Cost effectiveness for the patient, & Blue Shield

Based on such review, decisions are made on a case-by-case basis. When extra-contractual benefits are needed for risk-management contract subscribers, the coordinator seeks approval of the group, fully documenting needed resources and providing cost analysis of benefit savings.
d. Alternative care resources

In addition to utilizing health resources such as private duty nursing and skilled nursing facilities, case management makes use of home health care and hospice services provided by licensed community agencies.

These agencies provide an array of services including:

- Nursing care
- Physical, speech, occupation and respiratory
- Medical social services
- Nutritional/dietary guidance
- Prescription drugs and home care supplies
- Durable medical equipment
- Homemaking services
- Bereavement counseling for covered family members
- Respite care
- Facility hospice care for the final stages of terminal illness

Other community resources available under case management include:

- Crippled Children's Society
- American Cancer Society
- American Heart Association
- United Fund
- Church and community groups
- Local, state and national health associations
- Rehabilitation technicians
- Blue Shield's network of hospital discharge planners and social workers

e. Case management history

The case management program described in the preceding pages has been in existence as a pilot project for nearly one year. During this period Blue Shield has handled a variety of cases involving terminally ill patients, including cancer and AIDS patients. We have also worked with acute rehabilitation cases, premature infants and high-risk neonatal cases.

f. Advantages of this system

(i) The service continuum is working for the patient, depending on need

(ii) It is cost effective

(iii) With the other program goals assured case management provides options for the patient, the care provider and the payor.
f. (cont.)

(iv) It will provide an important data base for future cost of care analysis, while protecting patient confidentiality.

In providing an overall case management system, it will be important for the AIDS Treatment Centers to ensure all confidentiality, therapy patient referral, admission and discharge requirements of state statutes, and all utilization review and quality assurance requirements.

The patients comprehensive management plan should be forward to him/her upon discharge or transfer for post hospital care.

13. Professionally staffed comprehensive program of volunteer recruitment, training and support should be operated in conjunction with the AIDS Treatment Center.

The relationship between community care health service delivery, and volunteers has never been so important as in the AIDS crisis. Not only has the vanguard of volunteers in most rural and urban areas been the only consistent support system apart from hospital staff, but has made a significant contribution overall to health care costs for AIDS patients. A volunteer program could be divided into direct patient support by counselling, befriending, (based on San Francisco's Shanti model) or the utilization of mental health professionals who want to donate their services.

Volunteers should not be used (as in the past) to replace the services of a professional AIDS caregiver. Volunteers should enhance the quality of care and community support for the care of people with AIDS. Volunteer coordinators and trainers, such as at the Shanti Program and Aids Project Los Angeles should be available to staff the various AIDS Treatment Centers. A core curriculum and program standards should include: (1) methodology of a recruitment in the gay community, black, Hispanic and Asian communities (where appropriate); (2) the content and methodology of training for AIDS services; (3) data collection; (4) a system of recruiting; 5) tracking volunteer hours and types of service; (6) psycho-social support for volunteers directly involved in direct patient care; (7) AIDS education and prevention methodology for volunteers (who are also in high risk populations); (8) systems for volunteer recognition. Volunteers could also be trained and utilized for home help services such as shopping, light chores, and transportation for patients.
CASE MANAGEMENT MODULE 3

101 - 150 cases total
(These can be incrementally increased up to 600 clients)

FUNCTION
Administrator's office
Family data/epidemiost etc.
Assists with Revenues/Program

FUNCTIONS
Administrative Program
Liaison with Administration Centre
Staff Supervision
Reporting/Evaluation/Review

Discharge Planning
Resource Development
Client Advocacy
Counselling/Crisis Intervention

Supervises Staff mental health
Programs/Crisis Intervention
Supervises Volunteer Fund
Advocate for clients in need
Placement for dementia ellilolated

Recruits, trains, supplies
volunteer team
Schedules groups, programs
Liaises with other community services

Assist care worker with
clients needs
Advocates for client

FUNCTION
Administrative Assistant

CLERICAL ASSISTANT

FUNCTION
Assisting caseworkers + others

ADMINISTRATOR

CASWORKER 1

CASWORKER 2

MENTAL HEALTH SPECIALIST

VOLUNTEER CO-ORDINATOR

INSURANCE SPECIALIST (50%)

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LEGAL SERVICES

MENTAL HEALTH SERVICES (PUBLIC + PRIVATE)

VOLUNTEER EMOTIONAL PRACTICAL SUPPORT (COMMUNITY BASED)

RESIDENTIAL SERVICES

AIDS WARD(S)

DESIGNATED AIDS TREATMENT CENTER (HOSPITAL)

1 CASEMANAGEMENT MODULE 3 (UP TO 150 CLIENTS)

4 CASEMANAGEMENT MODULES (UP TO 600 PATIENTS)

SKILLED NURSING FACILITY (100+

OUTPATIENT FACILITY (UP TO 600 PATIENTS

HOME HEALTH + ATTENDANT SERVICES

RESIDENTIAL HOSPICE SERVICES

DRUG + REHABILITATION PROGRAMS

AIDS TREATMENT CENTER SERVICE MATRIX 86'-87.
Outpatient Staffing
600 patients

Chief R.N.

R.N.

R.N.

R.N.

Physician

Administrator

Physicians Assistant

Physicians Assistant

Administrative Assistant

Clerical/Receptionist

Part-time Consultants = 1 F.T. Physician

10 or 12 subspecialists part-time
Pulmonary, Oncology, Hem &...
II. Assessing Existing Services

During the past two months, five California counties have been selected for site visits by the consultants. The counties were selected for the following reasons:

(1) Their uniqueness; e.g. The problems and resources of the San Francisco and Los Angeles care continuum are unique to each metropolitan area.

(2) Patient numbers (Orange, El Dorado and Santa Cruz represent numerically different patient populations and differing developmental levels of service delivery).

(3) The ways of which existing services rely on existing resources (e.g. Santa Cruz does not have a county hospital facility or a university college hospital, and depends largely on physicians and the local health authority for care for AIDS patients).

(4) The relationships with service providers in neighboring counties in the provision of services and how patients utilized these services.

As we review these site visits, the goals which have just been discussed will be applied to what currently exists in these counties.
A. San Francisco County

B. Los Angeles County

(please read the Robert Wood Johnson proposal introduction. Client figures in Los Angeles have practically doubled since this proposal was written)

A complex network of AIDS service providers, churches, mental health programs, and hospitals provides services to Los Angeles' 2,322 AIDS population, an estimated 9,288 with severe (depending on definition) and 100,000 estimated HIV infected.

A recent report form the Public Health Service on a site visit to Los Angeles gives a contemporary view of the service needs (enclosed)

The County Health Department have recently hired a new Administrator who has called for a five year county plan for AIDS services which should be completed by October 1987. In the meantime the main issues affecting the Los Angeles Community which expects 15,000 AIDS cases diagnosed in 1991 and 150,000 estimated cases of ARC.

1. The need for countywide coordination, planning and long term development of services.

2. The need for skilled nursing facilities and hospice care for PWA's.

3. The need for cultural and ethnically sensitive programs of care in Hispanic and black communities.

4. The need for alternative community based programs to provide residential care for PWA's (shelters and subsidized housing).

5. The need for programs and services in areas of the city other than West Los Angeles i.e. Long Beach, Pamona, Pasadena, San Gabriel Valley, South Central Los Angeles etc.
AIDS IN SAN FRANCISCO:
STATUS REPORT AND PLAN FOR FISCAL YEAR 1987-88

REVISED*
MARCH 1987

San Francisco Department of Public Health

David Werdegar, MD, Director of Health
Jeffery Amory, Director, AIDS Office
George Rutherford, MD, Medical Director, AIDS Office

101 Grove Street, Room 323, San Francisco, CA 94102

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I. EXECUTIVE SUMMARY

AIDS IN SAN FRANCISCO: STATUS REPORT AND PLAN FOR FISCAL YEAR 1987-88 (REVISED MARCH 1987) is the third and final document in a series which has led to a plan and budget proposal for AIDS programs and services for the 1987-88 fiscal year. In December 1986, a STATUS REPORT AND PRELIMINARY PLAN was presented to the San Francisco Health Commission. A February edition included some corrections, some additional information about existing service configurations, more detailed recommendations about directions for 1987-88 and an analysis of the potential impact on the Department of Public Health's budget. This March version reflects some fine tuning and further refinement of specific budget issues. In the City/County budgeting process, "budget issues" are items which are not accommodated in the Department's "base budget".

The document begins with a description of the purpose and scope of the work done and the process undertaken in developing the report/plan. This is followed by a report of the number of cases of AIDS on record in San Francisco and the number anticipated by June 1988, and subsequently by a discussion of demographic trends and their implications for prevention and health care services. Particular concerns of women and racial and ethnic minority groups are addressed in separate chapters. The balance of the report/plan is organized around eight categories of programs and support services:

- Surveillance, epidemiology and related research
- Public education
- Provider education
- Clinical screening and acute medical care
- Chronic care and related support services
- Mental health services
- Substance abuse services
- Administrative support and coordination.

Most sections include a discussion of the nature of services/programs covered in the section, an identification of goals, a brief description of current service configurations, a summary of factors and constraints which have or will probably have a particular impact on services, reaffirmation of relevant departmental policy, an indication of the general direction in which program development is expected to move and a discussion of funding needed to make such development possible. Since the categories around which the document is organized are not mutually exclusive, there are frequent references to other parts of the document.

It is hoped that readers will appreciate the comprehensiveness of San Francisco's response to AIDS as well as the complexity of the problems being addressed.
The current epidemics of acquired immunodeficiency syndrome (AIDS) and human immunodeficiency virus (HIV) infection are the most serious health crises ever faced by the City and County of San Francisco. This document provides an overview of the current situation and identifies the general direction of programs planned by the San Francisco Department of Public Health (DPH) for the short-term future. It reflects several needs:

1. The need for an overview of the problems associated with managing the epidemic that have emerged to date and what has been done to address these problems.

2. The need for broadly-based community-oriented educational and prevention programs to limit the transmission of HIV.

3. The need to continuously assess:
   - how the epidemic is growing, what the impact of educational and prevention programs have been and what the demand for services related to it will be
   - what existing services will need to be expanded or modified and what new services will need to be developed
   - how to distribute the financial burden of the epidemic reasonably among private and public (local, state, national) agencies to maintain and expand these services
   - how to insure that planning and management related to the epidemic are well coordinated with governmental agencies and community organizations
   - what progress has been made toward the development of a vaccine and what progress has been made toward the development of effective therapy both for symptomatic and asymptomatic HIV-infected patients
   - the need for a clearer understanding of the constraints on the long range planning of responses to the epidemic.

This document has been organized around services currently in place and funded entirely or in part by DPH. Services of other providers are noted but discussed in less detail. It contains descriptions of current services and identifies unmet and/or emerging needs.
The recommendations contained in this report have been shaped by a variety of intramural and extramural committees, groups and reports. They include:

- DPH's Executive Committee and DPH's AIDS Committee
- Hearings conducted by the San Francisco Health Commission
- Reports on AIDS from the National Academy of Sciences and the Surgeon General of the United States Public Health Service
- Recently enacted State and Federal legislation regarding support for AIDS services
- Observations about established and anticipated patterns of contracting with State and Federal agencies
- Written descriptions of current AIDS services from San Francisco service providers
- Written descriptions of reported gaps in AIDS services and written proposals for expanded and new AIDS services from current service providers, advocacy groups and community-based organizations
- The Mayor's AIDS Task Force
- The Director of Health's Medical Advisory Committee on AIDS, AIDS Advisory Committee and Minority Advisory Task Force on AIDS.

The AIDS status report and plan should be viewed as a flexible working document which will change as the character of the epidemic changes. It should also be viewed as a reference document which can be used for planning the variety of services needed to deal with the epidemic. Finally, it should help place current and planned services in the context of managing the epidemic as a whole.

Unlike the December 1986 edition of the report/plan, which outlined general directions of programmatic development but did not include fiscal information, the report/plan in its February 1987 draft does include information about specific dollar amounts needed and sources from which they are likely to come.

The written descriptions of current AIDS services from San Francisco providers, from which most of the "current services" material is gleaned, have been edited for uniformity of format and some gaps in the information provided have been filled. A similar process was conducted with the written descriptions of perceived AIDS service gaps and proposals for expanded and new services. These submissions influenced the planning of services as it became more specific. They are being made available to the Health Commission under separate cover for reference.
III. DIMENSIONS OF THE EPIDEMIC IN SAN FRANCISCO

A. CURRENT EPIDEMIOLOGY OF AIDS AND AIDS-RELATED COMPLEX

1. AIDS

By January 31, 1987, 2,853 cases of AIDS and 1,707 deaths from AIDS had been reported to the Department of Public Health. This corresponded to an incidence of 420.2 cases per 100,000 population. The number of cases of AIDS diagnosed per month in San Francisco is continuing to rise (Figure 1).

The demographics of AIDS in San Francisco is shown in Tables 1-4. These include:

- 2,408 (84.6%) homosexual and bisexual men, 358 (12.6%) homosexual and bisexual men with histories of intravenous drug use and 34 (1.2%) heterosexual intravenous drug users
- 2,823 (98.9%) adult and adolescent men, 23 (0.9%) adult and adolescent women and 7 (0.2%) children
- 1,432 (50.2%) 30 to 39 years old, 726 (25.4%) 40 to 49 years old and 407 (14.3%) 20 to 29 years old
- 2,461 (86.3%) whites, 188 (6.6%) Latinos, 164 (5.7%) Blacks and 38 (1.3%) Asians and Pacific Islanders.

The proportion of gay and bisexual men with AIDS was lower among nonwhites [344/392 (87.8%)] than among whites [2422/2461 (98.4%)] (Table 5).

2. Other HIV-related diseases

Using estimates of the ratio between AIDS and ARC patients in cohort studies, we can estimate a range of the number of ARC cases in San Francisco:

- 4,246 to 22,824 total ARC cases (including lymphadenopathy syndrome)
- 2,389 to 19,908 cases of lymphadenopathy syndrome.

The ratio of 8.6 cases of ARC per case of AIDS is from a cohort study conducted in 1984, and the ratio of 1.6 cases of ARC per case of AIDS is from a subset of the same cohort infected for an average of 70 months examined in 1986. The proportion of ARC to AIDS cases appears to decrease with increasing length of infection. The true number of ARC cases currently is, because of the relatively short duration of HIV infection among gay men in San Francisco, probably closer to the higher estimate than the lower.
3. Numbers of HIV-infected patients using inpatient health care facilities

Approximately 7-10% of all living AIDS patients are hospitalized in acute-care facilities and up to 10% are probably in need of subacute, intermediate, or chronic care services at any given point in time. Additionally, there is about one ARC patient hospitalized for every 10 hospitalized AIDS patient in both acute and chronic care settings.

4. Numbers using publicly subsidized health care services

Between January 1985 and June 1986, 32% of all AIDS hospitalizations in San Francisco were at San Francisco General Hospital (Table 6). During this same period, 37% of all AIDS hospitalizations in San Francisco were reimbursed by public third party payors (MediCal, Medicare, etc.).

- of 435 public-third-party-reimbursed hospitalizations, 278 (64%) were at San Francisco General Hospital
- of the 70 self-pay hospitalizations, 48 (69%) were at San Francisco General Hospital.

B. PROJECTED EPIDEMIOLOGY OF AIDS IN SAN FRANCISCO

1. AIDS

Using mathematical modelling to project total AIDS cases, total living AIDS cases, AIDS cases by race and AIDS cases by major transmission categories (homosexual and bisexual men, homosexual and bisexual men with histories of intravenous drug use and heterosexual intravenous drug users), we predict:

By June 30, 1987, there will be:

- 3,297 cumulative AIDS cases (Table 7)
- 1,226 living AIDS cases
- 2,763 (83.8%) cases among homosexual and bisexual men, 422 (12.8%) cases among homosexual and bisexual men with histories of intravenous drug use and 46 (1.4%) cases among heterosexual intravenous drug users (Table 8)
- 2,822 (85.6%) cases among whites, 207 (6.3%) cases among Blacks, 219 (6.6%) cases among Latinos and 46 (1.4%) cases among Asians (Table 9).
By June 30, 1988, there will be

- 4,485 cumulative AIDS cases (Table 7)
- 1,449 living AIDS cases
- 3,756 (83.7%) cases among homosexual and bisexual men, 571 (12.7%) cases among homosexual and bisexual men with histories of intravenous drug use and 66 (1.5%) cases among heterosexual intravenous drug users (Table 8)
- 3,827 (85.3%) cases among whites, 291 (6.5%) among Blacks, 296 (6.6%) among Latinos and 66 (1.5%) cases among Asians (Table 9).

Significant changes in the length of survival of AIDS patients (for instance, from antiviral therapy) will increase the number of living AIDS patients.

2. Other HIV-related diseases

Using the same ratios between AIDS and ARC patients as above, we can estimate a range of the number of ARC cases in San Francisco to be:

- 5,143 to 25,354 total ARC cases with 2,963 to 24,728 cases of lymphadenopathy syndrome by June 30, 1987
- 7,176 to 38,571 total ARC cases with 4,037 to 33,638 cases of lymphadenopathy syndrome by June 30, 1988.

As these patients will likely have been infected longer than ARC patients in 1986 (i.e., there will be relatively fewer new cases of HIV infection) the true number of ARC cases will be more likely be closer to the lower estimate than the higher.

3. Projected numbers of HIV-infected patients using inpatient facilities and publicly subsidized health care services.

Needs for hospitalization may increase as effective antiviral therapy becomes available, leading to a higher percentage of living AIDS patients hospitalized because of more aggressive management of the disease and treatment of drug side effects. Additionally, as AIDS becomes more prevalent among intravenous drug users, there will be increased utilization of public-third-party reimbursement, potentially placing further demands on San Francisco General Hospital.
C. EPIDEMIOLOGY OF HIV INFECTION

1. Seroprevalence

Studies of cohorts of homosexual and bisexual men in San Francisco have found the prevalence of HIV infection to be between 33% and 73%. In a large population-based study conducted in San Francisco census tracts with relatively high concentrations of unmarried male residents, the current prevalence is 52%. Studies of methadone clinic patients in San Francisco found that the prevalence of infection was 10% in 1985. More recent estimates suggest this prevalence may have doubled in 1986. Population-based data are not available for other populations in San Francisco, such as heterosexuals with multiple partners, blood transfusion recipients and hemophiliacs.

Prevalence data from anonymous test sites are not population-based and do not accurately reflect the true prevalence of HIV infection either in the general population or in at-risk groups. The prevalence of HIV infection among blood donors in San Francisco is currently 0.05% with the prevalence among male donors 0.06% and the prevalence among female donors 0.04%. These data are also from a non-random population but have some utility as a reflection of the overall seroprevalence of HIV infection in the general population. Other data on the seroprevalence of HIV infection in San Francisco are available from military recruit HIV screening programs. During the first three quarters of the screening programs, the seroprevalence among recruits from San Francisco was:

- Overall, 0.75%
- 0.76% for men and 0.60% for women
- 1.67% for whites, 0.60% for Blacks, 0% for Latinos, 0% for Asians and Pacific Islanders and 0% for American Indians.

2. Seroconversion (Incidence)

Data from the homosexual and bisexual male cohorts suggest recent seroconversion rates of between 3% and 5% of uninfected men per year. No data are available for other at-risk groups or the general population.

Further population-based cross-sectional and cohort studies will be needed to ascertain more fully the true seroprevalence and incidence of HIV infection in the general population and selected at-risk groups.
SAN FRANCISCO
AIDS CASES BY MONTH OF DIAGNOSIS
(FORECASTS THROUGH 1988)

Note: CI stands for confidence interval.
PROJECT NARRATIVE

I. BACKGROUND AND STATEMENT OF NEED

INTRODUCTION

The political context through which Los Angeles County (LAC) health policy and planning is formulated is characterized by a multi-tiered system of responsibility. California state government oversees general regional policy, while the L.A. County Board of Supervisors determines overall policies and funding disbursements for the region. Los Angeles itself is the largest single city within LAC; 68 additional municipalities also operate their own city councils and civil service structures, with local ordinances and policies which impact PWAs. Santa Monica, West Hollywood, and Long Beach, as examples, have all provided service to AIDS-diagnosed populations through city allocation as well as through county funds.

The AIDS crisis has profoundly impacted the county health care system, but the response has been characterized until recently by fragmentary, rather than consolidated action. To begin to address this dysfunction, a series of meetings under the auspices of AIDS Project Los Angeles (APLA) and the Los Angeles County Department of Health Services (LAC/DHS) was held beginning in February of 1986. Working groups called Focus Groups were established around health service functions (e.g. inpatient/ambulatory care) and special population concerns (e.g. hispanic, black, pedatric). These groups were charged with profiling the existing services and identifying the unmet needs of their respective constituencies.

Primary service gaps and deficiencies appear at the level of coordination of the various nodal points and organizations in the service delivery continuum. Several areas and populations appear to have little or no services, such as intermediate nursing care, mental health services, ethnic minorities, and IV drug users. Recent institutional responses to AIDS by service providers have been crisis-oriented, uncoordinated, and, given the vast geographic and ethnic diversity of Los Angeles, lacking in centralized planning and leadership. The heart of the present needs statement focuses on the effort to ensure that LAC has a comprehensive and integrated system for health service delivery, to establish an infrastructure of health services coordination, and to provide sufficient access to those services for the client population. Above all, the plan is seen as a catalyst for an integrated and cooperative approach to AIDS services in the county—a process which is now well underway as a result of the Robert Wood Johnson initiative.

A. PROJECT SERVICE AREA

Los Angeles County is the largest urban complex on the Pacific Coast, and the 2nd largest SMSA in the U.S. It covers an area of over 4,000 square miles with a broad range of terrain and climate. Population centers lie scattered over the region, some in close proximity, some widely dispersed; the downtown area of the city of Los Angeles lies roughly in the center of this configuration. The Pacific Ocean forms the western border of the County; coastal cities include Long Beach,
Redondo Beach, and Santa Monica. The northwestern boundary of the County stretches through mountain terrain, and turns north over unevenly populated desert terrain for about 60 miles; the eastern border runs directly through the Antelope and San Gabriel Valleys on its way back to the Pacific.

B. THE GENERAL POPULATION

1980 census data places the total population of Los Angeles County at just under 7.5 million persons; estimates project over 8 million residents through 1985. 37% of these persons are between the ages of 15 and 34, and over 30% are 20 years old or less; only 42% of the population is over the age of 34.

L.A. County’s economic profile reflects a disparity in personal wealth, with extremes of affluence and poverty in close geographic proximity. In 1984, there were 2,866,000 households in the county, having a median annual income of $22,468 each, and an average annual income of $29,819, though 34% to 42% of county residents earn less than $15,000 per household annually, and 12.7% of the population earned less than $5,000 in 1980.

In terms of racial and ethnic composition, the county's overall character is changing rapidly. As of 1985, estimates show a white population comprising 47% of the population as opposed to 52.8% in 1980. Persons of Hispanic origin made up over 30% of county residents in 1985, versus 27% in 1980. Blacks have accounted for a relatively constant 12% of the population over those five years, while Asian populations constitute 10% of area residents.

C. THE TARGET POPULATION: PERSONS WITH AIDS AND ARC

The first U.S. cases of Acquired Immune Deficiency Syndrome (AIDS) were recognized and reported in 1981. Since that time, the nationwide total of reported cases has risen to nearly 21,000 cases through May 1986. The death rate among all cases to date has risen to 55%, with an average survival time of about 18 months.

Although numbers of ARC cases are difficult to determine, current estimates place the total prevalence at ten times the rate of diagnosed AIDS. Manifestations of the condition vary considerably; but it is clear that some individuals do die of ARC. Because the needs of ARC clients are so similar to those of AIDS, reference to the needs of the AIDS population in this proposal will include the ARC population unless otherwise specified.

In addition to the problems of AIDS and ARC, the CDC estimates that well over 1 million people in the U.S. will have been infected by the HTLV-III/LAV virus by the end of 1986. Based on current evidence, approximately 250,000 Californians are probably infected with the virus now, and many will go on to develop some form of the disease. All infected persons may be capable of transmitting the disease despite being asymptomatic. In the absence of an efficacious vaccine and adequate treatment procedures, the prevalence of all of the above conditions is expected to grow.

As of April 30, 1986, 1,749 cases of AIDS had been reported in Los Angeles County, with a mortality rate of 56%. LAC represents 9% of the national caseload and roughly one-third of the 4,700 cases within the State of California. By
AIDS HEALTH SERVICES PROGRAM
Project Abstract

Project Title: Los Angeles AIDS Resource Center and County Plan 1986-1990

Metropolitan Area Represented: Los Angeles County

Los Angeles County (LAC), a metropolitan region in Southern California with an area of over 4,000 sq. miles, provides services to the second largest AIDS-diagnosed population in the U.S. in a manner which is often fragmented, duplicative, and inadequate in meeting needs. In cooperation with the LAC Department of Health Services, AIDS Project Los Angeles (APLA), the leading AIDS service and networking agency in this region, proposes the utilization of funding from the Robert Wood Johnson Foundation, the U.S. Public Health Service, and many secondary sources to establish an infrastructure for the coordination, planning, management, and development of AIDS services in LAC with the following goals and objectives:

1. To improve service delivery through collaborative planning and coordination among provider, funding, and planning agencies, including the establishment of a Metropolitan Advisory Committee representing 90% of AIDS providers in LAC by 1988; a 27-member L.A. AIDS Resource Center Council to attain by 1990 sufficient prestige to be viewed as a principal source of advice and expertise in LAC; and a Los Angeles AIDS Resource Center, through which administrative and resource staff will operate a clearinghouse for existing care resources and expanded services and education throughout the county, with which 90% of LAC AIDS service providers will be both familiar and directly affiliated by 1990.

2. To reduce costs to the health care system in LAC, and increase the level of comfort for persons with AIDS, through improvement and expansion of out-of-hospital referrals and resources, including reduction of the average length of hospitalization for LAC AIDS patients to less than 12 days per stay, and total hospital time to less than 60 days, by 1990.

3. To assure the provision of adequate, culturally sensitive care and services to LAC minority populations, particularly Blacks and Hispanics, through the work of Coordinators and federally-funded staff operating in conjunction with established minority AIDS agencies. Objectives include the general education of 75% of minority populations, and the assurance of comprehensive education, care, and service access to 75% of HTLV-III infected individuals in these groups by 1989.

4. To institute an effective 'case-management' system for LAC by 1990, such that 75% of all persons with AIDS, 50% of all identified persons with severe ARC, and 75% of self-identified AIDS health service providers are by then voluntarily participating in an information matrix program assuring PWAs access to all available LAC resources, and facilitating appropriate referrals and early discharge by providers.

5. To provide adequate AIDS-related education and support for 90% of high-risk groups in LAC by 1990, including support related to maintenance of risk-reductive behaviors; and education in medical and social AIDS issues to 75% of LAC health care providers by 1990.

The present proposal describes a comprehensive system, planned and administered with the close cooperation of all major LAC AIDS provider agencies, and involving major funding from the U.S. Public Health Service. Funding requested through the AIDS Health Services Program represents an indispensable component in this master plan to meet the needs of all persons diagnosed with and at-risk for HTLV-III infection in LAC throughout the duration of this crisis.
PROJECT IMPLEMENTATION ACTIVITIES

Year 1: Establishment of Los Angeles AIDS Health Services Resource Center under auspices of APLA; expansion of Robert Wood Johnson (RWJ) Task Force to LA AIDS Resource Center Council (LAARCC); Metropolitan Advisory Committee (MAC) elects members to a 2-year term; implementation of matrix management system; formation of an Administrative Unit to oversee and manage program activities and gather relevant data; hiring of personnel for other staff positions through RWJF funding and PHS federal funding (this will include Hispanic and Black Community Coordinators to develop new and existing programs for targeted populations in satellite service units, key technical and resource coordinators for mental health, substance abuse, housing, and specialists in case management, extended care, home health care, and volunteer coordination); opening of shelters for PWAs; development and implementation of model extended care system in LAC; development of overall plans in service areas for establishment of education and training resource center as clearinghouse for informational activities; recruitment of Pew Fellows (thru UCLA) to assist in program activities targeted to physician education.

Year 2: Continuation of previous year activities; meetings of MAC and LAARCC ongoing; increase of hemophiliac and home health care specialists to full-time; Youth AIDS Coordinator augmented by 1/2 time caseworker; federal and/or state-funded HTLV-III testing sites open in East and South Central L.A.; increased staffing for AIDS-related activities for high-risk and minority populations from alternate funding sources; extension of networking to areas adjacent to Los Angeles to relieve burdens in outlying areas; expansion of skilled and intermediate nursing, home health, and attendant care service staff through Public Health Service funding extension; model computerized case management model operative; opening of shelters in minority areas; preparation of comprehensive evaluation of program activities and progress toward objectives at conclusion of year.

Year 3: Continuation of previous year's activities; meetings of MAC and LAARCC ongoing; second MAC election of LA AIDS Resource Center Council members for a 2-year term; outline by Development Specialist of fundraising plan to secure funding beyond grant term; continued expansion of alternatives to hospital care for PWAs/ARCs; shelter facilities expand further into LAC; outlying areas of LAC begin utilization of model programs for case management, facilities coordination, training, and prevention; expansion of AIDS-related staff by local government funding to LAC cities and San Bernardino County; Transportation Coordinator develops a countywide plan for clients; ongoing evaluation of program activities and outcomes; renegotiation of funding with Public Health Service to complete a 4-year service plan.

Year 4: Continuation of previous year activities; meetings of MAC and LAARCC ongoing; Development Specialist augmented by assistant to secure resources beyond year 4; increase in funding to support activities of resource development personnel; expansion of education, prevention, and health care services to minority communities; increased mental health staff in high-risk communities from other funding sources; expansion of model programs and opening of new SNF, INF, and freestanding hospice and shelters facilities in other areas of L.A.; negotiation of organizational and management systems with APLA and County Health Dept. for future of AIDS Resource Center and Council; finalize five-year AIDS service plan (1990-1995) for LAC and evaluate second cycle of RWJ/Public Health Service funding; evaluation and recommendations made to LAARCC, APLA Board, LAC Board of Supervisors, RWJ Foundation, and Public Health Service.

Acting Project Director: Paula Van Ness, Executive Director, APLA
Designated Applicant Organization: AIDS Project Los Angeles
Participating Organizations: L.A. County Department of Health Services; Orthopedic Hospital; Watts Health Foundation; Children's Hospital; many others (see list of participating organizations).

Form AHSP-2
extrapolation, an estimated 17,500 ARC cases currently exist within LAC. AIDS figures may reasonably be expected to continue to increase at the current rate within the County of approximately 3 new cases per day for the near future. As of April 30, 1986, the State of California Department of Health Services also reported that Los Angeles County has surpassed San Francisco County in cumulative cases. Based upon these trends, the LAC/DHS projects a total of 12,095 cases of AIDS by December 1990, which would represent a caseload 7 times the current County level within the next four years. The current estimated cost of care for an AIDS patient in LAC from diagnosis to death is $109,000 (cf. Qualitative Analysis of AIDS in Calif; Calif. Dept. of Health Services; 3/86).

Geographically, diagnosed AIDS cases are scattered throughout the County, largely clustered in centers of gay male and ethnic group residency. 34% of all diagnosed AIDS cases countywide, or 603 cases total, are located within the Hollywood-Wilshire health district, situated slightly east of the county's center; major concentrations also exist in the Central, East Valley, and Western health districts (please see addenda for AIDS cases by health district). The city of Long Beach represents a unique endemic focus in the county, with a 300% increase in number of cases from April 1985 to April 1986. This figure represents a cumulative incidence so far of 112 persons, and a prevalence of 32 cases per 100,000 inhabitants. The fact that the areas most impacted by AIDS are separated by relatively large geographical distances, and that transportation for persons with AIDS is frequently problematic, has necessitated the concentration of AIDS inpatient services in several different facilities throughout the county. (Please see addendum)

While the potential population groups at risk for AIDS and ARC may well be unlimited in number, initial cases since 1981 have largely affected specific population groups. By far the largest group is gay and bisexual men, accounting for 94% of all AIDS cases in Los Angeles County (1,603 cases) out of a LAC/DHS-estimated population of at least 500,000 gay and bisexual men. And although heterosexual IV drug users account for 3% of AIDS cases, at least 12% of all diagnosed persons (212 cases) have a history of IV drug abuse along with other risk factors. Females account for 21% of all IV drug abuser cases, 26% of AIDS cases contracted through heterosexual contact, and 26% of all transfusion cases, yet account for only 2% of the AIDS diagnosed population (39 cases). In terms of age, nearly 50% of all cases are among individuals in the 30-39 year range, with 40-49 year-olds accounting for 23% of cases, and 20-29 year-olds composing 18%. Pediatric cases (children under 5) presently account for 1% of AIDS cases in LAC, but the number of undetected pediatric cases may make these totals much higher.

Within LAC, whites represent 71% of the total AIDS caseload, as opposed to 59% nationwide. Of other affected populations, Blacks represent 14% of all cases, Hispanics 13%, and Asians and other groups 2%. Among gay and bisexual men, these percentages are comparable, as 12% of gay and bisexual cases within the county are black, and 13% are Hispanic. Among IV drug user cases, 32% of heterosexual IV user cases are Hispanic, and 34% are black. Virtually all pediatric cases have been among minority children. The higher incidence of IV drug use presents imminent threats to the minority populations whose consequences may only be beginning to be felt.

Hemophiliacs represent a risk group largely attributable to viral transmission through utilization of Factor VIII and Factor IX. The hemophiliac population in LAC is estimated at 750 - 800 persons; clinicians at Orthopaedic Hospital estimate that 70% to 80% of patients with congenital coagulative disorders in LAC, or 450 persons, are likely to be HTLV-III positive.
D. SPECIAL HEALTH AND SUPPORT NEEDS OF PERSONS WITH AIDS AND ARC

The course of AIDS has been adequately documented in the scientific literature, and the severity and spectrum of disease presentations in Los Angeles County do not differ markedly from the national profile. It has already been demonstrated that cases are spread throughout the 4,000 miles of the county, thus making access to the various services available a complicated matter. The AIDS Project Los Angeles/Robert Wood Johnson planning team undertook a community diagnosis approach to the identification of needs through establishment of 13 ongoing focus or task-oriented groups from 70 AIDS-related agencies who explored resources and service gaps within specific interest groups or service areas. Many other research studies and reports, along with direct PWA input, have been utilized in the development of a plan for a service-oriented continuum of care, with the following categories identified as being necessary to meet the needs of persons with AIDS or ARC in LAC: AIDS Outpatient Services (Ambulatory Care); AIDS Inpatient Services; Intermediate and Extended Care Services; Home Health/Hospice Care Services; Mental Health Services; Dental Care; AIDS Screening and Testing; Support for Daily Living; Emergency and Long-Term Housing; Case Management Services; Health Care and Social Service Advocacy; Legal Services; AIDS Education; and Support for Special Populations.

E. HEALTH AND SUPPORT SERVICES AVAILABLE FOR PERSONS WITH AIDS AND ARC

F. GAPS AND DEFICIENCIES IN SERVICES FOR PERSONS WITH AIDS AND ARC

G. PRESENT EFFORTS TO MEET NEEDS

The individual focus group reports prepared as part of APLA's Robert Wood Johnson planning process have identified currently available services within specific program areas, new services now under development, and gaps in service needs. We have combined sections E, F, and G throughout the following to provide a summary of resources and needs specific to each service area. These condensed reports on LAC service provision present a combined picture of the state of AIDS care within the county, and lead into the primary goals and objectives defined in subsequent sections of the proposal.

1 & 2. AIDS OUTPATIENT AND INPATIENT SERVICES are provided across the County through an extensive network of public and private facilities. Three medical schools - University of California, Los Angeles (UCLA); LAC/University of Southern California (USC), and Charles R. Drew Medical School at Martin Luther King, Jr. Hospital - provide care through a network of teaching units, while hundreds of private hospitals and public clinics provide intermittent care. A network of community identified private physicians also see substantial numbers of AIDS and ARC patients, as well as provide service to high-risk individuals.

According to a September, 1985 survey by the Hospital Council of Southern California, 66% of LAC hospitals have already treated AIDS patients. The average length of stay per hospitalization of 17.3 days, versus 6.3 for all other patients, with AIDS patients averaging 2 or 3 hospitalization periods in the course of their illness. Countywide, overall hospitalization may be decreasing; LAC/USC Medical Center reports that the average length of stay for an AIDS patient is down from 21 days a
year ago to 17.3 days as of May 1986, due in large part to the increase in alternative care programs. Sherman Oaks Community Hospital, provider of the majority of inpatient care in the San Fernando Valley, and dispenser of a wide variety of supportive services and referral lists, reports an average length of stay of approximately 11 days.

Among health care facilities providing treatment to AIDS/ARC populations, LAC/USC - a 2200-bed general hospital financed by the County of Los Angeles and professionally staffed by the faculty of the University of Southern California - is by far the largest in the area. The 187 patients seen in 1985 represent 24% of the AIDS patients diagnosed in LAC that year, and the 318 patients admitted from the beginning of the AIDS epidemic through 10/85 represent 23% of all patients reported in LAC. The facility also currently treats 350 individuals with ARC through the AIDS outpatient clinic. Since the appearance of AIDS, the outpatient department has seen upwards of 1,000 patients for AIDS-related consultations regarding nursing services, social work, physician care, and financial services. The facility admits no private patients, and so has few problems in controlling both admission and reporting. There is presently no committed AIDS ward; current hospital policy is that AIDS patients are cared for more efficiently according to primary infection. LAC/USC works closely with other hospitals and public agencies on AIDS-related research within the county.

At UCLA Medical Center, 124 patients with CDC defined AIDS (16% of LAC cases) and 158 persons with ARC were treated during 1985. UCLA provides a range of services to the patient through its cooperative arrangements with the university's schools of social work and public health. Harbor/UCLA Hospital in Long Beach treated another 125 cases (16% of total) during 1985. The latter facility is operated in cooperation with and through funding by the LAC/DHS; although neither facility has a dedicated AIDS ward, both have fully functioning and staffed outpatient clinics for diagnosis and treatment of AIDS. A third major County-funded facility - Martin Luther King/Charles Drew Hospital - serves residents of central county areas, and accounts for several AIDS intakes monthly. According to LAC Department of Health Services statistics for the month of April 1986, the average daily census of AIDS patients in county hospitals was: LAC/USC Medical Center: 23.4; Harbor-UCLA Medical Center: 4.2; Martin Luther King-Drew Hospital: 1.0. The Wadsworth Veterans Administration Medical Center Hospital near UCLA has already seen 75 AIDS-diagnosed individuals total through May, 1986, and Veterans Administration Hospital in Long Beach several more.

Sherman Oaks Community Hospital in the San Fernando Valley (northern section of the county) has the only dedicated AIDS ward currently operative within LAC. In 1985, the facility treated a total of 65 cases (8.4% of countywide total), but already in 1986, has treated 110 cases through June 1 (12% of ytd LAC total; 1,474 patient days through May 1). An affiliated private medical clinic is responsible for outpatient/ambulatory treatment.

Other hospitals and medical centers providing a high volume of outpatient and inpatient AIDS services include: Loma Linda University Medical Center in east county; Cedars-Sinai Medical Center in Beverly Hills; Kaiser-Permanente Medical Centers, which insures 1.8 million Southern Californians, and have provided services for approximately 150 AIDS patients; St. John's in Santa Monica; Good Samaritan in downtown L.A.; Hollywood Community Hospital; St. Vincent's Hospital in Hollywood; and 4 out of 10 Long Beach facilities, including St. Mary's and Long Beach Memorial.
place for assuring adequate quality of care across the system. Results of a preliminary survey of LAC physicians by UCLA Dept. of Medicine indicate deficits in knowledge of the disease and its management, as well as lack of awareness of availability of home care services, resulting in extremely inadequate early discharge of patients to such systems. In LAC, it has been conservatively estimated that up to 30% of all AIDS patients currently in hospital could be discharged today if adequate facilities for intermediate skilled home care existed. There is insufficient financial coverage for short and long-term home patient care needs, a factor which discourages patient participation in such programs, and a need for making insurance providers aware of the financial advantages of subsidization of out-of-hospital services. Training programs are needed to target potential volunteer providers of home attendant care as a cost-reduction step, and to insure that care from members of existing patient support groups (e.g. family members) is adequate. It is also instructive to observe that, according to LAC/DHS reports, 78% of all AIDS-diagnosed individuals who died during the month of March did so in hospital; 21% died in their homes; and none died in either a nursing home or hospice. Aside from both the immense costs and discomfort to the patient represented by the in-hospital deaths, preliminary surveys indicate that a demand for hospice care would exist for a substantial percentage of diagnosed cases if the facilities were in place and publicized. The creation of dedicated hospice facilities, the expansion of subsidized in-home hospice care, the training of adequate numbers of AIDS-specialized hospice personnel, and education and networking to promote regular referrals and early discharge by hospitals is a major priority.

5. **MENTAL HEALTH SERVICES** for AIDS and AIDS-related conditions are available through APLA, the Gay and Lesbian Community Services Center (GLCSC), Shanti Foundation, and a network of therapists and social workers in hospitals and in private practice. The Los Angeles County Department of Mental Health is also providing a limited amount of service. Mental health needs manifest themselves in varying ways, in terms of fulminant disease and associated depression/anxiety, as well as organic brain syndrome, creating special training and personnel demands, such as for mental health peer counseling programs. In addition, HTLV-III positive populations and those at risk have made increased use of mental health facilities, resulting in unprecedented strain on the ability to deliver services. The GLCSC reports a current waiting list of 3 months before mental health treatment of AIDS-impacted populations. A need exists for support services of all types for health workers dealing with AIDS patients as well as for members of patient support groups.

6. **DENTAL CARE** for persons with AIDS is provided through the R.E. Greene Dental Treatment Center in West Hollywood, operated by APLA in conjunction with the LAC Department of Health Services, and staffed by volunteer dentists and dental assistants. The Clinic sees an average of 80 patients per quarter for an average of 400 hours of treatment, with an ongoing waiting list of approximately 20 individuals. Treatment is provided regardless of ability to pay. The number of individual dentists willing to provide fee-basis services to persons with AIDS in other public or private practices is not known. Particular dental manifestations affecting diagnosed populations include oral candidiases, oral neoplasms, and acute exacerbation of periodontal disease. Los Angeles City Attorney David Shulman, responsible for reporting of discrimination cases, announced in April 1986, that his office had received over 80 complaints regarding denial of dental services which may prove to sufficient for litigation; this is a clear mandate for greater education and service provision by dental personnel. The need for
intention to develop a 100-bed designated care facility for persons with AIDS/ARC, to include super-skilled, skilled, and board and care nursing in a three-floor configuration; completion is expected within 3 years. No listing of provider organizations presently exists - this is essential for encouraging referrals and initiating networking. Greater education in the realities of AIDS transmissibility for INF and SNF staff and management is needed to remove the barriers of fear which often prohibit admission of AIDS patients; a program of volunteer assistance training is also needed. Increased insurance advocacy for patients in obtaining reimbursement will greatly increase the number of individuals availing themselves of extended care opportunities.

4. HOME HEALTH/HOSPICE CARE SERVICES. Home health services are provided by several major agencies in the county, some of which have specialized training programs for employees in AIDS-related care. The largest of these is the Visiting Nurses Association (VNA) of Los Angeles, and its affiliated agency, Visiting Nurses Home Health. The latter agency saw 120 patients in 1985, and has so far seen over 50 new patients during the first four months of 1986 alone. The number of AIDS patients cared for by the VNA's Home Health/Hospice program has increased dramatically from 6 patients in 1984 to 87 during the first 4 months of 1986. The VNA reports that the average length of home nursing service per patient has also risen, from an average 46 days in 1984 to 55 days in 1985. Hospital Home Health Care and San Pedro Peninsular Home Care in the southern county, National Medical Homecare in central Los Angeles and National In-Home Health Services in the northern county also provide service. In general, home nursing agencies have not displayed the reluctance in treating AIDS patients that has been shown by skilled nursing facilities. However, although approx. 60% of PMA's are Medical eligible, MediCal pays for only the nursing portion of home care services, and not the home attendant care which is equally important in keeping the individual out of the hospital and reducing costs. APLA itself has funded the attendant care costs for an ongoing average 25 patients at a time for the past year, with assistance from private contributions, the County of Los Angeles, and the State of California, while a separate $440,000 State of California Dept. of Health Services grant to AIDS Project Los Angeles will fund an in-home skilled nursing and attendant care demonstration project for 125 individuals in the County through April 1987.

Hospice care services are currently available in institutional and in-home formats, with the VNA providing in-home care through its Hospice in the Home Project. Several other home nursing agencies, such as Hospice of the Good Shepherd in Los Angeles's inner city area, provide continuation services into terminal phase of illness, and have been willing to accept AIDS patients. The Veterans Administration Hospital in West L.A. operates a hospice which accepts AIDS patients, though only 2 patients have been seen through May 1986. Although no dedicated AIDS hospice currently exists in Los Angeles, several plans are underway to institute such facilities, including those by the Episcopal Diocese and the Catholic Archdiocese of L.A. Hospice support services are presently provided through Shanti Foundation in terminal stage by volunteers; a portion of the APLA State Home Care grant will fund the cost of home hospice care for approximately 25 individuals this year.

No comprehensive inventory or listing of providers to persons with AIDS in LAC currently exists; a designated staff person to profile and coordinate these services is essential. A need exists for a definition of training and care standards AIDS-related home health care workers, and no system is in
improved countywide training in AIDS transmissibility to dental professionals, and the compilation of referral networks for use by case management agencies, is evident.

7. AIDS SCREENING AND TESTING is available in the central county through the County-funded Edelman Health Clinic and AIDS Prevention Clinic at Hollywood's Gay and Lesbian Community Services Center (GSCLC) and in the south, at Long Beach STD Clinics operated by The Center/Long Beach in cooperation with the Long Beach Health Department. Services are free of charge, available to anyone, and testing procedures at both sites include pre- and post-counseling. The Edelman Clinic administers an average of 150 HTLV-III antibody tests per week; two Long Beach test sites handle many additional clients per week, although 26% of the Long Beach clients come from Hollywood and the San Fernando Valley, and 11% from East L.A. Present demand does not currently exceed availability of services.

8. SUPPORT FOR DAILY LIVING represents an ongoing need for all AIDS-diagnosed individuals. Thus far, it remains largely the province of the AIDS/ARC diagnosed individual's personal support group. Service provider augmentations of such assistance occur mainly through APLA, Aid for AIDS, the Center/Long Beach, and Minority AIDS Project. APLA provides assistance through the work of 200 trained volunteers paired with persons with AIDS/ARC to provide daily living assistance, chore service, companionship, etc., for an average 8 hours per week. Minority AIDS Project provides similar services through a less structured program. Aid for AIDS provides direct cash grants to persons with AIDS to subsidize costs related to daily living, and provides direct financial counseling to PWA's through subcontract with APLA's State Home Care grant. Chore services are available through the VNA and several other homecare agencies for a cost of approximately $10 per hour throughout the county, but such services are not normally covered by standard health care plans. APLA provides a transportation service for client needs, subsidizing fuel through its general funds. Both Minority AIDS Project and APLA provide emergency food and clothing, maintained mainly through private donation, although APLA also receives some federal funding (FEMA) for its food program. APLA also operates a Necessities of Life Program which solicits contributions of goods from manufacturers and suppliers, and distributes them to PWA's through a free store format. Other suppliers of emergency food and shelter throughout the county have seemed receptive to extending services to persons with AIDS.

Gaps exist in the provision of food, but the full need is not currently known, as such programs have never been widely publicized as related to AIDS. Current volunteer programs which match individuals with PWA's are in constant demand, and must be more actively recruited for to meet anticipated case increases. Community-level programs that increase awareness of the potential of volunteer support to PWA's must be expanded, as must recruitment of volunteer support group leaders and training in emotional support issues. Transportation services must reach all corners of the county in order to assure that patients seek adequate care and have access to all resources.

9. EMERGENCY AND LONG TERM HOUSING needs are met through an uncoordinated system of largely unpublicized programs within the County. These programs have developed in response to needs as they have arisen over the last two years only. Through private contributions, APLA operates an emergency housing voucher program which, during 1985, placed 34 persons who would otherwise have had no place to stay in hotel rooms for an average of 14 days.
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Major AIDS research centers providing access to experimental treatment and to more intense private case history monitoring exist at UCLA Medical Center (approx. 1500 clients in AIDS Natural History Study, and hundreds of clients in clinical, drug treatment, and HTLV-III biological studies); and LAC/USC Medical Center (approx. 100 patients in generalized lymphadenopathy study since 1982; 100 patients in asymptomatic gay control group study since 1982; and 44 patients in AIDS lymphoma treatment study). Several specialized drug trials are also underway at USC.

LAC/USC Medical Center, as a key nodal point in the county's overall ambulatory/inpatient care configuration, is a major hub for coordination of countywide AIDS care. UCLA's planned AIDS Clinical Research Center likewise serves as an excellent focal point for research coordination, including shared results of clinical trials, laboratory resources, education, and creation of a data library. The county-affiliated Harbor/UCLA Medical Center currently lacks any personnel support for coordination of services to AIDS patients, including transportation, discharge planning, and volunteer coordination, which are presently handled by hospital personnel not trained in extra-hospital AIDS service availability. At Sherman Oaks Hospital, the intense flow of AIDS patients through the dedicated ward of this medium-sized hospital has created a need for coordination of support services to patients, particularly to handle the training and recruitment needs related to volunteer services at the facility.

AIDS inpatient and outpatient services must be coordinated and linked throughout the county, in order to create an effective plan of action for care over the coming years, and to assure consistency of care, provide adequate service to affected populations and sufficient training of personnel, and facilitate allocation of resources to reduce costs and eliminate duplication. It is believed that a centralized facility for service coordination, staffed by individuals trained in public health administration and planning, is needed to obtain accurate profiles of providers in order to identify available services and reasons for the existence of service gaps, and to begin to develop improved ambulatory and inpatient care through resource coordination, health care worker education, and advocacy to government and funding agencies. A centralized system should also be developed to allow hospitals and outpatient facilities to have access to comprehensive listings of extra-hospital facilities and services available to AIDS patients in LAC, in order to assure adequate out-of-hospital care for patients, and to facilitate and encourage early discharge.

3. INTERMEDIATE AND EXTENDED CARE SERVICES available through specific facilities have been difficult to identify. A questionnaire regarding intermediate nursing facility (INF) and skilled nursing facility (SNF) usage in the Los Angeles area distributed as a part of community needs assessment for this proposal reveals that, of 138 responding skilled nursing facilities from all regions of the county, only 3 had admitted any AIDS patients since 1981, and of those, 8 total patients had been accepted - this despite the fact that 51 facilities had received a combined total of 214 inquiries for service. No INF or SNF in LAC currently provides advertised care on a regular basis for persons with AIDS and ARC. While the average hospitalization cost per day for a PWA is $830 to $1,100 per day, the cost of nursing home care is closer to $150-$250 per day - a cost-reduction to patient and provider. Since only 3 or 4 skilled nursing facilities have yet been identified as providing care to AIDS patients throughout LAC, a need for greater access is apparent. Beverly Enterprises has declared its
through which all providers were notified of existing resources for patients, and all persons with AIDS were informed of services available to them, would greatly contribute to the reduction of AIDS-related costs, and the improvement of patient comfort. There is presently no such centralized case management provider in the county to which the majority of facilities make referral which has the capability of reaching population in all corners of the huge LAC region except for APLA, which copes with a growing case-managed client base despite problems of access and distance. No master plan for the future exists, and no central means of gathering referrals and publicizing case management to providers is in operation. A means through which services may be coordinated with other counties, particularly those bordering LAC, will assist in assuring adequate care for persons in peripheral regions.

11. HEALTH CARE, LEGAL, AND SOCIAL SERVICE ADVOCACY are ongoing functions of the Los Angeles County Department of Health Services, which prescribes policy and advocates for health services funding at the county level. Both state and local advocacy is provided by elected officials, as informed in part by medical providers and, especially, by social service agencies active in the AIDS battle. The four full-time case managers at APLA, regular hospital staff social workers, and volunteer legal staff, provide ongoing advocacy to PWA's. A paid financial counselor at APLA, financed by the State of Calif. Health Services Department, provides debt management and public insurance application assistance. At present, advocacy efforts are mounted on a case-by-case basis, with little emphasis on overall coordination as it relates to short and long-term policy planning and implementation. There is a need for cooperative efforts with the insurance industry in order to implement cost effective measures, such as third party payment for in-home attendant care. Legal services are provided through public assistance and governmentally-administered programs. The Gay and Lesbian Community Services Center maintains a panel of volunteer lawyers to deal specifically with AIDS-related issues, including emergency legal services, to which APLA makes referrals; demand far exceeds litigational capacity. The major gap in AIDS-related legal service is the lack of a coordinated system of legal advocacy, including contingencies for the provision of low-cost litigation services.

12. AIDS EDUCATION is a large and ongoing function of several county agencies, led by the L.A. County Dept. of Health Services, which both funds and operates a wide variety of risk-reduction and general public information projects. Previous efforts, focusing largely on gay and bisexual populations through risk-reduction education and counseling, continue through the CARES TEAM program (formerly L.A. CARES) of the GLCSC, which includes media outreach and materials distribution. APLA now operates the Southern California CARES program, a mass media educational campaign featuring radio, print media, and television messages to sensitize the general public and reach non-self-identified gay and bisexual men; the program is a joint venture of ten AIDS agencies from throughout Southern California. The AIDS Project Los Angeles AIDS Information Hotline provides toll-free education and counseling to all of Southern California for 80 hours per week via trained volunteers; approximately 5,000 calls per quarter are responded to. The APLA Speakers Bureau presents information through a volunteer staff to approximately 2,000 persons per month. (All three programs are financed by the State of Calif. Health Services Dept.) Largely through the efforts of community-based agency programs, local media, health, and governmental bodies have gradually begun to assume some of the responsibility for education; health care facilities staff training of all kinds is also on the rise.
Despite this myriad of existing and developing programs within the county, no centralized resource/referral center currently exists for cataloging and distributing available materials on general and specific AIDS-related publications, brochures, videos, journal articles, etc. Such a facility, providing CAIN-accessed computer banks, and accessible by individuals, community and health agencies, the media, etc., would be an invaluable tool for the consolidation and networking of educational resources, and for the avoidance of service duplication. Training of AIDS providers in media relations is needed to assure professional representation and advocacy for AIDS-related issues and needs. Large gaps exist in the provision of education to minority groups within Los Angeles County, including culturally-sensitive outreach to disparate social milieus, and production of materials in Spanish; Minority AIDS Project will continue to expand its educational outreach programs through materials and forums, and other programs in design stages by the LAC/DHS and APLA will meet more of these needs before the end of 1986.

13. **SUPPORT FOR SPECIAL POPULATIONS** is a major area of concern given the nature thus far of AIDS and high-risk groups. Gay and bisexual men have historically been the focus of the majority of extant outreach and education throughout the county, e.g. through GSCLC, APLA, Shanti Foundation, the Center in Long Beach, and Aid for AIDS, the latter through direct cash grants to PWA's. Minority AIDS Project, in conjunction with several black community organizations, provides outreach and education to the black communities of Los Angeles County with private funding resources. LAC/USC Medical Center serves many of the Hispanic population centers in central L.A. and treats the vast majority of Hispanic AIDS-diagnosed individuals; White Memorial Hospital, the Red Cross, El Centro Mental Health Center, and Aid for AIDS also provide Hispanic-related services. APLA employs a full-time bilingual case worker, a full-time Spanish-speaking minority outreach coordinator, and a part-time bilingual health educator. 20% of the client population of APLA are persons of color. The Drug Abuse Program Office of the LAC/DHS is responsible for overseeing county-funded drug abuse programs and agencies; treatment services are provided by the UCLA Neuropsychiatric Institute, the Watts Health Foundation, and Rio Hondo Drug Counseling in the eastern county; Minority AIDS Project, Shanti Foundation, and APLA provide chemical dependency counseling and referrals. Hemophiliac individuals are treated mainly through the Orthopedic Hospital and Childrens Hospital of Los Angeles, with a combined population of 619 patients with coagulation disorders; at present, all cases of AIDS have occurred within this group. Children's Hospital and UCLA Medical Center are almost exclusively responsible for the care of pediatric AIDS cases, although children with AIDS have been treated at Cedars-Sinai, Harbor/UCLA, and Loma Linda Medical Centers. Children's Hospital programs provide support to young mothers including counseling in prospective birth risks through the Florence Crittenton Center, and sexual counseling for adolescents, including IV drug users and gay male prostitutes, through the High Risk Youth Project, a venture funded by the Robert Wood Johnson Foundation.

Special populations support needs reinforcement in all areas, but represents a particularly obvious gap on the level of service to minority populations. Both Black and Hispanic community leaders and AIDS patients stress the need for tailored, easily-accessed community education regarding transmissibility, symptomology, and available testing, treatment, and counseling services. In order to encourage persons to seek adequate counseling and care, such education must strive to overcome the stigma attached both to AIDS and to self-identification as a member of a high-risk
group within these communities. Training for minority community health care providers, especially physicians and staff of community clinics and treatment centers, and of employees of minority service and governmental assistance agencies, is needed to assure responsive care and encourage patients to seek treatment. Lack of access to mental health and psychological support resources is also a problem, particularly as west county providers are frequently perceived as lacking sensitivity to central county community issues and needs. The problems of low-income persons with AIDS are magnified in minority communities. The costs of medical care and the lack of emergency services, particularly in terms of subsidized food and shelter, are a major concern. Greater networking between minority providers would target needs and improve overall education; compilation of a thorough listing of minority care providers would further the necessary work of education and training materials dissemination. HTLV-III/LAV testing sites should be established for convenient access by minority persons. The current overrepresentation of pediatric AIDS cases among minority populations is expected to increase through IV drug user mothers and through female partners of closeted homo/bisexual men; a system for dealing with this growth is overdue. Fear of being reported to authorities is a barrier to seeking treatment for many illegal immigrants; community-based and public providers must assure individuals that care may be sought safely. A large percentage of prisoners with AIDS in California are Black or Hispanic; research to determine their post-incarcerational needs will be a significant factor in assuring adequate attention for these persons. Currently-effective English-language materials must continue to be translated into Spanish by social service agencies. APLA and the County of Los Angeles, through partial CDC funding, will establish a Spanish-language information hotline in central L.A. before August 1986; APLA's State of California educational contract for fiscal year 86-87 will include funding for the institution of a minority speakers bureau.

Services for both high-risk and diagnosed chemically dependent populations must be identified and coordinated throughout the county to assure consistency of care, adequate service to affected populations, sufficient and standardized training of personnel, and extensive sharing of resources to reduce costs and eliminate duplication. These programs should be coordinated through the L.A. County Drug Abuse Program Office to assure centralized service. There is a need for crisis intervention and counseling services to drug abuse clients with AIDS-related problems, and a great need for education of these populations through service centers and materials development and dissemination.

Individuals with clotting disorders need further information regarding transmissibility, as well as improved counseling and support services given the high incidence of seropositivity within these populations. Educational and treatment approaches which parallel those necessary for other risk groups must be sensitive to the particular needs of hemophiliacs. No staff persons currently exist within the county to deal with this group in relation to AIDS.

The treatment and ongoing monitoring of pediatric AIDS cases must be coordinated and publicized throughout the county, in the latter case for purposes of physician referrals to adequate treatment facilities. Support for families of such cases, training in home care, and, especially, the education and counseling of prospective high-risk mothers, are strong needs if active steps are to be taken to reduce future pediatric numbers. Few counseling and direct AIDS education programs currently exist for
adolescents for whom issues of developing sexuality will present serious risk factors in the future without adequate information at an early age. Issues of care for orphaned children of persons with AIDS is another frequently overlooked childhood need. The County Dept. of Childrens Services is developing a plan for special foster homes for children with HTLV-III infections. All services must be surveyed, coordinated, and a general plan of action produced for pediatric AIDS treatment and response.

Finally, greater emphasis must be placed upon the emerging but still largely unknown at-risk categories represented by prison populations and by prostitutes. Outreach at all levels of community service must continually target these groups in order to identify emerging needs and to begin to develop adequate education and service resources accordingly.
In response to a request by Dr. Samuel Matheny, Director of the Office of AIDS Service Program of the Public Health Service, Mr. Robert Hummel and Dr. Judith Simmons of the New York State Department of Health conducted a site visit to the LAC-USC County General Hospital. The objectives of this visit were to familiarize ourselves with the Los Angeles County AIDS situation, the current programs and the future plans, and share our own experiences in AIDS related programming and service delivery. Representatives of the LA County of Health Service, Dr. Michael Finn and Mr. Rob Saltzman, were joint hosts with members of the LAC-USC County Hospital staff.

The site visit involved a review of both the general services available for people at risk of AIDS in LA and a review of the role of the Medical Center in delivering both inpatient and outpatient care within a continuum of care model. This review is based on the documents made available and the presentations offered by both Medical Center and County officials during the two day site visit.

The criteria used for the generic evaluation of AIDS programs and services in LA involved the following:

- Evidence of a basic structure to ensure that a continuum of care model is feasible for future AIDS service delivery

- Provision of access points to the health and social services system from racial, geographic and systems perspective

- Coordination of care through the presence of a principle coordinating agency

- Nonduplication of services through a central administrative structure

The criteria used for the specific analysis of the medical center's capacity for the delivery of AIDS related care included:

- Evidence of a continuum of care capability including both systems and staffing aspects

- Procedures to facilitate patient follow up for both inpatient and outpatient care

- Appropriate scheduling procedures for the outpatient clinic

- The presence of a structured case management system inclusive of both medical and nonmedical criteria.
It should be emphasized at the outset that the site team was impressed with the level of commitment, the program development and the services provided to people with AIDS by a group of individuals working within a complex political and underresourced program. Neither the observations nor the recommendations found in this report should be construed as a negative comment on individual programs or staff.

The first day of the visit included an overview of AIDS/HIV infection in LA, an introduction to the LA County Department Health Services/LAC-USC County Hospital HRSA grant proposal, an introduction to the LAC/USC County Medical Center and a tour of the facilities. Along with Dr. Finn and Mr. Saltzman, the following representatives of the LAC-USC County Hospital were present:

Dr. Sol Bernstein, Medical Director, LAC-USC County Hospital
Dr. John Bethune, Medical Director, Internal Medicine
Dr. John Leedom, Section Chief Infectious Disease
Dr. Fred Sattler, Coordinator, Interdisciplinary AIDS Service
Dr. Peter Hezeltine, Epidemiologist
Dr. Alexandra Levine, Oncologist, Interdisciplinary AIDS Service
Mr. Richard Brock, R.N., Nursing Director Internal Medicine
Mr. Michael Hedderman, R.N., Nurse Manager AIDS Service
Mr. Richard Condoka, Administrator General Hospital
Mr. Dick Pacheco, Administrator

The following day a meeting was held with Dr. Finn, Mr. Saltzman and Dr. Hezeltine to address the role of Department of Health Services and specific details of the grant. The visit concluded with a reconvening of the group joined by Dr. Matheny and Dr. Robert Treguada, Dean of the USC Medical School. Preliminary verbal recommendations were offered, followed by a lively discussion by the group. This report is a summary of our impressions, evaluations and recommendations.

BACKGROUND:

Los Angeles County is the largest urban complex on the Pacific Coast, and the second largest Standard Metropolitan Statistic Area (SMSA) in the U.S. It covers an area of 4,000 square miles with a board range of terrain and climate. Population centers lie scattered over the region with the downtown area of the City of Los Angeles situated roughly in the center of this configuration. The Pacific Ocean forms the western border of the County; coastal cities
include Long Beach, Redondo Beach, and Santa Monica. The northwestern boundary of the County stretches through mountain terrain, and turns north over unevenly populated desert terrain for about 60 miles; the eastern border runs through the Antelope and San Gabriel Valleys and returns to the Pacific.

1980 census data places the total population of Los Angeles County at just under 7.5 million persons. It is estimated that there are now over 8 million residents. 37% of these persons are between the ages of 15 and 34, and over 30% are 20 years old or less.

In terms of racial and ethnic composition, the County's overall character is changing rapidly. As of 1985, estimates show a white population comprising 47% of the population as opposed to 52.8% in 1980. Persons with Hispanic origin made up over 30% of County residents in 1985, versus 27% in 1980. Blacks have accounted for a relatively constant 12% of the population over those five years, while Asian populations constitute 10% of area residents.

The political context through which Los Angeles County (LAC) health policy and planning is formulated is characterized by a multi-tiered system of responsibility. California state government oversees general regional policy, while the L.A. County Board of Supervisors determines overall policies and funding disbursements for the region. Los Angeles, itself is the largest single city within Los Angeles County; Eighty-three additional municipalities also operate their own city councils and civil service structures, with local ordinances and policies that impact persons with AIDS (PWAs). Santa Monica, West Hollywood, and Long Beach, as examples, have all provided service to AIDS diagnosed populations through city allocation as well as through County funds.

As of December 31, 1986, there was a cumulative total of 2553 AIDS patients in Los Angeles County. This represents nine percent of the national caseload and about one-third of the cases within California. Of those cases, 98% were men, 2% were women and 15 were children. 45% were between the ages of 30-39 and the overall mortality rate was 61%. 94% of the men were homosexual or bisexual and 2% of the cases had a history of intravenous drug use. 70% of the AIDS cases were white, 14% black and 15% hispanic; the majority of the pediatric cases have occurred among the minority population.
Geographically, diagnosed AIDS cases are clustered in centers of gay and ethnic group residency. Thirty-four percent of AIDS cases are located within the Hollywood-Wilshire health district. Major concentrations also exist in the Central East Valley and Western health districts. The location of death for 16% of AIDS cases was at county hospital facilities, 54% died at other local hospitals and 24% died at home (11/86 data).

LAC-USC County Hospital Staff members and the LA County Department of Health Services representatives estimate that the LAC-USC Hospital is the lead provider in the county, caring for 20% of all new cases and 30% of all living patients. The average daily AIDS/ARC inpatient census was 23 in December, 1986, with an outpatient clinic population of about 600 patients. They estimate that the Kaiser Sunset Hospital (800 beds) is the second largest provider, with a 15-20 AIDS/ARC patient census, the other 8 area Kaiser hospitals having a joint AIDS/ARC patient census of 15-20. Of the other County hospitals, Harbor-UCLA reports an average census of 5 inpatients, Martin Luther King, Jr./Drew Medical Center a 0.5 inpatient census and Olive View Medical Center a 0.9 inpatient census. Other hospitals noted to be serving large numbers of AIDS patients include: UCLA Medical Center, Sherman-Oaks Community Hospital (dedicated AIDS ward), Cedars Sinai Medical Center, Hollywood Community/Midway Hospital and Loma Linda University Medical Center. The Edelman Health Center and private practitioners provide a significant portion of the outpatient care.

The LAC-USC County Hospital is a 2,200 bed medical center financed by the County of Los Angeles. Over 90,000 patients are admitted per year to the medical center, including 40-60 medical service admissions per day. The great majority of which are through the Emergency Room or "Walk In" Emergency Area. The inpatient medical service has a general medical ward (50% of the beds) and discreet subspecialty units including pulmonary, communicable diseases, and others. The hospital staff estimates that 4% of all inpatient medical service beds are AIDS related admissions, though for certain individual wards this percentage is considerably higher i.e. 20% on the pulmonary unit and 25% on the communicable diseases ward. AIDS patients consume 10% of all hospital days, with an average length of stay of 18 days (ALOS of all other patients is 6 days). The clinic supports 670 patient visits per month, including about 50-60 new patient visits.

In June, 1986, the AIDS Project Los Angeles in cooperation with the LA County Department of Health Services and a number of other AIDS service providers from the LA County area, applied to the Robert Wood Johnson Foundation for
funding support. The grant focused upon the coordination and integration of AIDS Health Services in LA County but was not accepted for funding. In September of 1986, the proposal was revised and submitted by the LA County Department of Health Services to the Public Health Service for funding.

The objectives, as outlines in the grant application include:

-- To expand case management model to Harbor-UCLA, LAC-USC Medical Center and various community agencies

-- To strengthen outpatient clinic services twofold: a) enhance medical care; b) focus on corresponding data

-- To provide broad spectrum AIDS/ARC training for non-acute providers

-- To maintain/update a resource inventory to assist in the provision of care for AIDS/ARC patients

-- To implement a comprehensive data collection and analysis system at the LAC-USC Medical Center and AIDS Program Office

-- To provide technical assistance to local health jurisdictions and community agencies.

The LA County Department of Health Services, LAC-USC County Hospital and UCLA-Harbor County Hospital were the main recipients of the funding, with 8 subcontracts approved for inclusion. These subcontractors are:

AIDS Project Los Angeles
Beverly Foundation
City of Long Beach
Los Angeles Shanti Foundation
Minority AIDS Project
Watts Health Foundation
Orthopedic Hospital
El Centro Human Service Corporation.

PROGRAM REVIEW:

As stated in the project description, the overall goal for the project is to assure that Los Angeles County has a comprehensive, integrated system of health service delivery for persons with AIDS, ARC, and HIV infection by 1990. This
goal is projected to be achieved through utilization of both County and Public Health Service funds, as well as other funding sources. The implementation of the project involves the coordination of both new and existing health care resources as well as the development of new AIDS specific health and social services. Some of the overall AIDS project objectives identified in the materials presented include:

1. The establishment and management of an infrastructure of AIDS related service providers and agencies, technical experts and planners, and advocates and policy makers, whose goal is the improvement of service delivery through collaborative program planning, prioritization of needs and allocation of resources;

2. The reduction of in-hospital costs and overall increase in patient satisfaction with received care through the reduction in both the average length of stay per hospitalization and the overall cumulative total of hospital days per patient;

3. The provision of adequate care and service to minority populations, including facilitation of access to services, information, and resources, and the inclusion of minority community members at all levels of AIDS service planning and implementation throughout the county;

4. The development of a client focused, comprehensive AIDS case management system for Los Angeles County;

5. The adequate education of high risk populations in AIDS transmission, prevention and the institution and maintenance of risk-reductive behaviors, and the sufficient training of health care providers in LAC to assure appropriate care, and to encourage the expansion of services.

The site review team focused the role of two major participants in the grant proposal, specifically, the AIDS Program Office and the LAC/USC Medical Center.

The County of Los Angeles, through the Department of Health Services is the responsible organization for the AIDS Project Demonstration Grant. The AIDS Program Office is administratively responsible for the implementation of those functions relating to the Outpatient Clinic at Los Angeles County-USC Medical Center, the Harbor UCLA Medical Center, and the Drug Abuse Program Office. As such, the Program Office is responsible for outpatient hospital resources, the coordination of provider profiles and the technical training of all health care providers.
The AIDS Program Office is also responsible for the monitoring of contracted activities related to the positions provided in the grant.

REVIEW FINDINGS:

The initial impression of the LA County AIDS delivery system was of a lack of centralization. Due to the vast geographical area and diversity in governing bodies, centralization of the services is a difficult, but an essential task. Although the Robert Wood Johnson funding application focused primarily on collective planning and coordination, there was less of an emphasis on these strategies in the HRSA grant.

In our experience, a strong coordinated services framework is crucial to avoid both redundancy and gaps in services and to permit effective future planning. It is necessary in order to assign responsibility, and to hold each facet of the program accountable. In the HRSA proposal, 7 of 12 cooperating groups seek to fulfill case management duties. Though this may be geographically easier, there is concern over a service too thinly spread and a lack of accountability.

In the initial RWJ application three committees were projected for establishment:

1. Metropolitan Advisory Committee - structured to represent the majority of the AIDS providers in LA County.

2. LA AIDS Resource Center Council - to be viewed as the principal source of advise and expertise in LA County.

3. LA AIDS Resource Center

We support the reconsideration of establishing these committees, under the auspices of the HRSA grant, with the AIDS Program Office acting as facilitator. We believe this will help to unite all facets of LA AIDS services, in addition to serving as a focus for community activity.

As outlined in the objectives of the LA County-PHS grant proposal, expansion of the case management model and strengthening of the outpatient clinic are top priorities. The USC-LAC Hospital serves a large portion of the AIDS patients in LA and is the primary focus for the expansion of patient case services. As with the vast geographical reach of LA, the enormity of USC-LAC Medical Center makes a strong
organizational base essential. A formal plan for the continued development of USC-LAC's services is pivotal for the success of the program.

This structure should include interacting levels of services between providers and within individual providers. This includes inter-county liaisons, as well as intra-hospital liaisons. The Emergency Department, the Pediatric Department and the Woman's Hospital need to become integral parts of the AIDS programming. The Department of Medicine, as the leader in this project, must clarify the roles and responsibilities of other departments and divisions in the Medical Center.

Continuity of care requires a network of formal linkages between hospital inpatient/outpatient and community services. Currently, continuity at LAC-USC County Hospitals is maintained by nurse clinicians who follow their outpatient panel of patients, upon admission to the hospital. Individual physicians, as well, are expected to follow their own patients when they are admitted. Although this system has been felt to be successful by the staff at LAC-USC, in our experience, as the patient load increases there is potential for lapses. Many large programs have structured a formal system establishing an AIDS team. This team generally includes a physician, a nurse, and a social worker. Their function is to be the liaison between outpatient and inpatient care facilities and to be the identified AIDS resource for all the other services within the hospital center, including the emergency service. It is essential that a team member be available around the clock for consultation.

The clinic at USC-LAC currently services approximately 600 patients, with sessions five times per week/two sessions per day. There has been a very successful integration of the subspecialty services within the primary care clinic structure. This centralizes services, promotes continuity of care, and should be maintained.

Clinic appointments are scheduled using a staggered block system recently inaugurated to reduce waiting time. There is planning in progress to create blocks of clinic time for phone in questions, emergency walk-ins and prescription refills. We support all of these interventions and can only suggest rapid implementation using the additional resources provided for in the grant award.

The clinic is staffed by attending physicians, both providing primary care and subspecialty care; house officers, on a monthly rotation; fellows; physician
assistants; nurse clinicians and social workers. To further improve continuity of care, we suggest the use of permanent practitioners in the clinic as opposed those on a rotation. This has been achieved in other centers by reducing the role of house officers and replacing them with full time nurse practitioners or physician assistants. Other AIDS programs have also made use of these physician extenders as screening practitioners for less severely ill patients or for "the worried well."

The social work service is markedly understaffed. It is unrealistic to expect a social worker to fulfill case management duties with a roster of 200 patients. We strongly support the incremental staff, as requested in the proposal, and strongly encourage increases as funds become available.

Finally, though not specific to this grant proposal, we believe that the strongest counterpart to a comprehensive outpatient facility is a designated inpatient unit. This serves to centralize inpatient care and services, provide a firm liaison to outpatient care and act as a focal point for community involvement. We acknowledge the difficulties in establishing such a unit, and can only advise, of our experiences as a positive addition to AIDS care.

RECOMMENDATIONS

General

1. Establish the AIDS Program Office as the central policy and planning agency for both inpatient and outpatient service delivery in L.A. County.

2. Review plans to establish committees described in the RWJ grant application:
   - Metropolitan Advisory Committee
   - LA AIDS Resource Center Council
   - LA AIDS Resource Center

3. Clarify roles and responsibilities of coordinating and contracting programs. Encourage increasing involvement by the Harbor-UCLA County Hospital and the Martin Luther King/Charles Drew Hospital.

4. Strengthen ties with other AIDS services providers in the LA area, not affiliated with this grant, including Kaiser-Permanente Medical Centers, local Veterans Administration facilities, Sherman Oaks Community Hospital, Loma Linda University Medical Center, and Cedars-Sinai Medical Center.
5. Continue AIDS/HIV infection educational efforts, emphasizing drug using minority women of childbearing age and adolescent communities.

6. Initiate, through the AIDS Program Office, the development and implementation of county wide case management standards, service definitions and performance criteria.

7. Develop, through the AIDS Program Office a five year plan outlining service networks, educational initiatives and social services systems necessary to cope with the projected increases in HIV in L.A. County

USC


2. Establish an intra-hospital committee on AIDS, to include representatives of all involved services and worker groups, i.e., Department of Medicine, Infectious Disease Section, Epidemiology, Emergency Medicine Department, Woman's Hospital, Psychiatry Department, Pediatrics Department, Nursing, Social Work, Ancillary staff and hospital administration.

3. Create an AIDS team composed of a physician, a nurse and a social worker to be available 24 hours a day for consultation on patient care and case management issues.

4. Maintain current centralization of clinic services, use of staggered block appointment scheduling and planning for discreet blocks for phone-in, emergency walk-in and prescription refills.

5. Phase out house officer clinic participation and replace with full time, non-rotating physician extenders (i.e., physician assistants, nurse practitioners).

6. Increase social worker staffing, aiming for under 50 active cases per social worker.

7. Reconsider the establishment of a designated AIDS inpatient unit.
C. Santa Cruz County

The Santa Cruz site visit was important because it concentrated on a physician based health care system without a county hospital or university hospital. With a small number of AIDS cases, this community, with a dedicated core of care providers was able to maximize community resources for their patients with AIDS and ARC.

A local physicians association had established an AIDS Task Force, working closely with the local health officer. A few physicians (6) were seeing the majority of AIDS/ARC patients with one particular physician seeing 60% of AIDS/ARC patients. This physician has also begun clinical drug trials with 3 of his patients. There was an expressed need for physician education and the Physicians AIDS Task Force was going to develop a plan in the next few months.

Anonymous blood testing was available through the County Health Department Clinic where pre and post test counselling was given. The clinic had a waiting list for testing until July 1987. A new AIDS coordinator had just been appointed. Sally Blumenthal, as the former coordinator had developed a comprehensive county-wide AIDS resource guide.

Santa Cruz Community Hospital, Watsonville Community Hospital and The Dominican Hospital were all providing care for people with AIDS/ARC. The latter had also provided convalescent nursing services to 7 AIDS patients. Visiting Nurses Association provided in home health care and the Santa Cruz Aids Project ($90,000.00 budget) provided overall case management through its psychological support system of volunteers, and practical support volunteers. Volunteer case managers were coordinated by the project director (who is former nurse manager at Dominican Hospital) and met on a monthly basis to discuss client needs. This team also involved a local hospital worker and the attending physician. There was a need to expand social services to clients and include legal expertise for clients. On average the 53 volunteers spent about four hours per week with the Santa Cruz clients. Volunteers heard about the project through media and public forums on AIDS, and consist of 1/3 gay males, 1/3 lesbian, and 1/3 heterosexual.

There were weekly support groups in Santa Cruz for HIV positives, people with ARC and AIDS (staffed by volunteers). Psychotherapists meet monthly with 'buddies' Practical support teams, education and speaker's bureau, hospital nurses also meet monthly. There was no formal meeting for support or education for physicians, hospital nurses, dentists, clergy or other principal caregivers.

The County's Substance Abuse Program requested AIDS protocols from contracts by the end of last year. These policies would deal with admission of HIV positive to shelters, detox programs, staffing issues, confidentiality, etc. The County
C. Santa Cruz County (cont.)

has 3 primary drug treatment providers and 2 alcohol treatment providers serving 35 people in adult residential care (there is a waiting list of 3-4 weeks) 80 - 90 adults in outpatient care, 2500 on the drinking/driving program and 100 people in drug diversion.

The residential facility is not prepared to take care of someone with AIDS. Substance Abuse Coordinator recounted a story of one patient who told other residents in a detox program he was HIV positive and the program emptied. The economic problem this caused (the program is based on fee for service) cannot be minimized. However outpatient care seemed to be more suitable for patients requiring dual treatment HIV infection/drug counseling or methadone treatment.

One County's contracts is with California Health Associates who also run programs in Contra Costa County, Pittsburg and Richmond. This counseling and treatment center has started an AIDS program with changes in admission criteria to service at risk individuals - for detox the 7 day Federal time frame for treatment eligibility replaces the 28 day timeframe for HIV infected individuals. At least 2 clients in the program are HIV positive. The staff expressed concern at the need for immediate voluntary blood testing of clients at intake. Clients who would agree to take the test, have to wait several days or weeks and not get tested. If testing was available at intake, the staff felt this would help to treat the high proportion of IV drug users who they suspected were sharing needles and were seropositive, and would help epidemiologic tracking and prevention. There was also an expressed need for County staff to do pre and post test counseling with this population and were in need of training 25% - 30% of clients were either engaged in prostitution or were sharing needles.

There are no plans for a residential facility which would deal with HIV infected substance abusers. One user who was dying from cancer went outside of the county to die. The community of Santa Cruz is developing a small shelter program for the homeless.

Precedent has been established for a tri-county shelter programs between Santa Clara, San Benito and Santa Cruz. Hermanos 10 is a program for Hispanic women funded by a Federal block grant.

Santa Cruz is one of the top 5 counties in the State funding residential and outpatient treatment programs and has the usual problems of being utilized by surrounding and other counties. The estimated cost of a 10 bed recovery home for 10 patients is $150,000 and the cost and the cost of a 35 bed facility is $317,000. this could possibly be an intra-county regional program.
C. Santa Cruz County (cont.)

The main issues which surfaced at this site visit were:

1. The need for easier access to HIV testing, particularly among IV drug users and training for their counsellors.
2. The need for South/County based programs for the Hispanic farm worker community.
3. The need for local physician education, support and organizing in the absence of a teaching hospital.
4. The need for an organized group practice or outpatient clinic where physicians could be helped with the administration of clinical drug trials and AIDS related services.
5. The improving of the Medi-Cal reimbursement rate which particularly affects economics and morale of those front line physicians who are prepared and willing to work with the HIV infected population who require more time than other patients.
6. The need for a support system and information sharing forum for existing care providers.
7. The need for expansion of HIV treatment programs in substance abusers in outpatient and residential facilities.
8. The need for a professional case management system which does not rely totally on volunteers.
9. The need to develop facilities to care for homeless and indigent people with AIDS; people with AIDS and dementia and people with AIDS who have substance abuse problems and cannot be placed in the existing system (These programs could be developed with neighboring counties e.g. Monterey has 36 AIDS cases 1/2 of whom are drug users, San Benito has 1 case and Santa Cruz has 40 AIDS/ARC cases.
10. Physicians could utilize the county laboratories to do HIV antibody testing.
11. There is need for this county to work more cooperatively with other counties in this region as the AIDS epidemic worsens. The local health officer is looking to the Health Officers Association of California's 9 Bay Area Counties Regional Plan as a possible next step.
12. There is no evaluation or system to monitor patient satisfaction for existing programs.

D. Santa Clara County

As part of a regional survey of the Santa Cruz area, I spent the afternoon with the service providers in Santa Clara now serving 183 AIDS cases, an estimated 1189 ARC cases and 13,725 HIV positives, 85% of the AIDS population is white, 13% Hispanic and 1.6% Black.

Similar problems exist with IV drug users with difficulty in placing people in programs. The providers were unaware if AIDS related services were being provided to this population. Principal hospitals serving the target population included
Valley Medical Center, Stanford, Kaiser Permanente and Santa Clara Community Hospital. A local AIDS Task Force composed of key service providers and public health staff has developed a 5 year plan projection of services needed and estimated costs which will be useful to this process (enclosed).

Aris is the local AIDS agency with its 101 volunteers and 53 active clients (21 PWA's) 10 ARC, 22 grieving) Catholic Social Services is expanding a shared housing project for people with AIDS while Aris is exploring a hospice program. There is presently no case management in Santa Clara County and providers say it is really needed. A shared housing project sponsored by the Catholic Social Services is particularly interesting and could be utilized by other organizations throughout California. (An executive summary of the Regional Approach to AIDS Service Delivery in the Greater Bay Area is enclosed in this section).
September 22, 1986

Bernard Cordes, M.D.
Santa Cruz Co. Health Officer
P.O. Box 962
Santa Cruz, CA 95061

Dear Dr. Cordes:

Enclosed is a new Executive Summary for the concept paper I recently sent you entitled "A Regional Approach to AIDS Service Delivery in the Greater Bay Area." Also enclosed is an improved printing of Table 1.

I look forward to your comments and suggestions regarding the paper. One major recommendation has been made to include Monterey and Santa Cruz Counties in the Greater Bay Area Region. These Counties have 25 and 17 AIDS cases, respectively, as of August 30, 1986. The Health Officers report that many of the individuals with AIDS that reside in these Counties seek medical care (particularly specialty care) in San Francisco.

Your suggestions regarding additions or revisions are welcomed. Please contact me during the week of October 6th with your comments.

Thank you.

Sincerely,

Carol Span
Assistant Director for Planning and Research

CS: mc

Enclosure
EXECUTIVE SUMMARY

Between June 30, 1985 and June 30, 1986, the number of persons with AIDS -- both in the U.S. and California -- doubled. This dramatic increase in AIDS cases is challenging both public and private health care providers and all levels of government to carefully assess service delivery capacity and resources that can be dedicated to individuals with AIDS. The tremendous economic and social consequences of the AIDS epidemic dictate a critical examination of the epidemiology of the disease and the availability of public and private resources and services in order that health care and social services to persons with AIDS are provided appropriately and efficiently.

This paper proposes the need for a study of a multi-county regional approach to AIDS service delivery in order to maximize available resources and offer appropriate and adequate services to persons with AIDS within a region.

The concept of a regional system for AIDS-related services raises some important planning and policy issues:

- The impact of migration into a highly-impacted city (e.g., San Francisco) of persons diagnosed with or suspected of having AIDS
- The relationship of service volume to the quality and efficiency of service provision
- Whether a community-based continuum of care can be supported and sustained on a regional basis
- Appropriate sources and mechanisms of payment for persons with AIDS
- The growing need for AIDS health education (community, school-based, and individual) and support services
- The impact of changes in medical practice
- The applicability of regional AIDS service delivery approaches to the management of other health problems
- The applicability of a regional approach to providing adequate services to county jail inmates with AIDS
- The applicability of a regional approach to other regionwide public health problems and activities
The need for increased communication and coordination among the major providers of AIDS-related services and community groups.

All of these issues are discussed in this paper and will be addressed in more depth in the proposed study.

In order to determine the appropriateness of a regional approach a study should be conducted to assess: 1) what public health and treatment components can/should be included in a regional model; 2) the extent to which existing secondary and tertiary care services already developed for persons with AIDS in the region can be used as the core of a regional service delivery system; 3) the extent to which surrounding localities with fewer AIDS cases should individually or in tandem develop their own specialized services and programs; and 4) if a regional approach is appropriate for a given region, how it would be implemented.

This paper proposes that a study be conducted in the Greater San Francisco Bay Area because of: the impact of the growth in AIDS cases in all counties in the region (not just San Francisco County); the established continuum of services developed in San Francisco; the geographic proximity of the counties and their major cities, and; the established service and professional networks that exist in the region. However, the concept of a regional approach to AIDS service delivery could be applied to any of the major AIDS impacted regions of the U.S. such as Los Angeles/Southern California, Miami, New York, and New Jersey.
### Table 1
REPORTED AIDS CASES 1985 and 1986
NINE SAN FRANCISCO BAY AREA COUNTIES
(Rank Order by Total AIDS Cases)

<table>
<thead>
<tr>
<th>County</th>
<th>AIDS Cases</th>
<th>Percent of Total</th>
<th>AIDS Cases</th>
<th>Percent of Total</th>
<th>Percent Increase in AIDS Cases June 30, 1985 to June 30, 1986</th>
<th>Cases Per 100,000 Population (June 30, 1986)</th>
</tr>
</thead>
<tbody>
<tr>
<td>San Francisco</td>
<td>1,117</td>
<td>81.1</td>
<td>1,912</td>
<td>76.5</td>
<td>71.2</td>
<td>257.8</td>
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<td>Alameda</td>
<td>96</td>
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<td>217</td>
<td>8.7</td>
<td>126.0</td>
<td>18.0</td>
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<tr>
<td>Santa Clara</td>
<td>43</td>
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<td>94</td>
<td>3.8</td>
<td>118.6</td>
<td>6.7</td>
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<td>San Mateo</td>
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<td>2.8</td>
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<tr>
<td>Sonoma</td>
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<td>66</td>
<td>2.6</td>
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<td>9.2</td>
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<tr>
<td>Contra Costa</td>
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<td>2.9</td>
<td>157.1</td>
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<tr>
<td>Marin</td>
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<td>53</td>
<td>2.1</td>
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<td>23.3</td>
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<td>Solano</td>
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<td>10</td>
<td>0.4</td>
<td>233.3</td>
<td>1.1</td>
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<td>2.0</td>
</tr>
<tr>
<td>Total AIDS Cases</td>
<td></td>
<td>100.0</td>
<td>100.0</td>
<td></td>
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<tr>
<td>SF Bay Area</td>
<td>1,377</td>
<td></td>
<td>2,499</td>
<td></td>
<td>81.5</td>
<td></td>
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<tr>
<td>State of Calif.</td>
<td>2,685</td>
<td></td>
<td>5,188</td>
<td></td>
<td>93.2</td>
<td></td>
</tr>
<tr>
<td>SF Bay Area AIDS Cases as % of State of CA AIDS Cases</td>
<td>51.3%</td>
<td></td>
<td></td>
<td>48.2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total AIDS Cases, US</td>
<td>11,352</td>
<td></td>
<td>22,173</td>
<td></td>
<td>95.3</td>
<td></td>
</tr>
<tr>
<td>SF Bay Area AIDS Cases as % of US AIDS Cases</td>
<td>12.19%</td>
<td></td>
<td></td>
<td>11.3%</td>
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A Report of
The Santa Clara County Board of Supervisors' TASK FORCE ON AIDS

Presented to the Board of Supervisors
March 17, 1987
1. **EXECUTIVE SUMMARY:**

The Task Force obtained data from a variety of sources to develop predictions for the number of AIDS cases in Santa Clara County by 1991 and for the medical costs and needs as a result of these cases. We conclude that by 1991 there will be approximately 3,400 cases of AIDS and 22,100 cases of ARC diagnosed within the County. The medical costs to care for these patients in 1991 will be approximately $144 million. Cumulative costs will be much greater.

The Task Force estimates that approximately one-third of the county's AIDS patients may seek care at the Santa Clara Valley Medical Center (SCVMC). To care for these patients, the Task Force recommends that:

**Recommendations for Medical Needs:**

1. The County should expand its resources at Santa Clara Valley Medical Center. This would include recruitment of a supervising specialist physician to coordinate and supervise activities related to AIDS.

2. The County should assist in the development of community resources. The number one priority is the development of a specialized hospice or skilled nursing facility for post-acute care.

3. With the guidance of the Hospital Conference and the Medical Society, each hospital should develop policies to facilitate care of AIDS patients. They should be able to identify physicians who are knowledgeable about AIDS treatment and are familiar with community resource services.

4. A long-term answer to the problem posed by AIDS lies in research. Research by county employees and other persons in the county should be encouraged from all levels of government, and by private and corporate support.

**Recommendations for Education:**

Until a vaccine for the AIDS virus is developed, the only way to slow down the spread of AIDS is through education. Education must be intensified and the media utilized to the fullest if non-infected people are to escape infection. Education must be directed toward all groups in the population, and culturally-sensitive materials must be developed. To accomplish this, the Task Force recommends that:

1. A wide-range of printed and audio/visual materials should be produced or purchased, including materials targeted to Latinos, Blacks, Asians, American Indians, women and youth.

2. An additional health educator should be hired to develop educational programs, do outreach to schools, and to assist in the presentation of educational programs in the schools.

3. An additional health educator should be hired to develop and deliver programs on women's issues.
4. An AIDS Clinical Nurse Specialist should be hired to provide expertise to clinics currently operated by the Santa Clara County Health Department.

5. Additional funds should be allocated in future years to produce and update AIDS educational materials and to hire more personnel.

6. The Board should work in a collaborative manner with external funding sources, groups and organizations to provide the widest possible distribution and development of educational materials.

Recommendations to Meet Social Service Needs:

As the number of AIDS cases increases in the County, the demand for services provided by County departments and contract agencies will increase. We investigated programs and services available to AIDS patients and made recommendations on how to meet the present and future needs. The Task Force recommends that:

1. An Adult Service Worker Team should be created to assist AIDS/ARC clients with SSI advocacy, health placement services, eligibility requirements, and supportive counseling in each DSS district office. Placement and funding of this team needs further exploration.

2. Mandatory ongoing training in AIDS-related issues should be provided by the Health Protection's AIDS Project to all DSS personnel who have direct contact with AIDS/ARC clients. This includes receptionists, eligibility workers, social workers, and their supervisors. Such training should also be required for Public Guardian workers on the same basis.

3. AIDS/ARC patients need to have priority service due to the immediacy of the disease. These priority services would include reserved vouchers for housing, appointment scheduling and in-home support services.

4. Contract agencies need a stipulation in their agreements with the County to provide AIDS training to their personnel, i.e., home-health workers, residential substance abuse program personnel, etc. Further, their agreements should explicitly specify the provision of services to AIDS clients who are eligible for them.

5. A multidisciplinary approach to delivering services to AIDS/ARC patients should be established. This would involve a team of trained personnel that would coordinate the delivery of comprehensive health care services to the client in order to facilitate case management.

6. The position of Multidisciplinary Team Coordinator should be created to ensure the efficient delivery of services to AIDS/ARC clients and to avoid duplication of efforts.

7. The Board should refer to the Paratransit Coordinating Council the recommendation that service providers work in cooperation with the ARIS Project to guarantee transportation of AIDS/ARC clients.
Recommendations to Meet Psychosocial Needs:

1. The contract with ARIS Project should be renewed in fiscal year 1987-88. In all probability, an increase in funding in fiscal year 1988-89 will be necessary.

2. County Mental Health should provide in-house training to contract agencies to guarantee that they respond properly to the psychosocial needs of AIDS/ARC clients.

3. All Mental Health district offices should be required to have a representative on the Mental Health Committee for AIDS.

4. A tracking system to measure the impact of AIDS/ARC on Mental Health services should be established.

5. All contract agency contracts should include provisions to provide services to eligible people who have AIDS or ARC.

Recommendations to Meet Housing Needs:

1. The Board should direct the Administration and County Counsel to include language in all contracts to require that service not be denied individuals with AIDS/ARC when providing the following:
   * Day Center Activities
   * Low Income Housing
   * Independent Care Services
   * Respite Care
   * Hospice Care
   * Skilled Nursing Care
   * Day Care

2. The Board should direct the County Executive to report back within 90 days on the need through 1991 for additional housing facilities and services that may be necessary for people with AIDS/ARC.

Recommendations to Meet Needs in the Jails:

The Task Force investigated the protocol issued for the jail which requires that AIDS and ARC inmates, and inmates who test positive for the AIDS antibody, be placed in medical isolation at the main jail. We recommend that:

1. The policy to put HIV antibody positive inmates in maximum-security medical isolation should be discontinued.

2. HIV antibody positive inmates should be granted the same privileges as other inmates, such as full participation in work furlough programs and trusteeships.

3. Ongoing AIDS education should be made available to all inmates, and be mandated for male and female inmates who have been sentenced. A procedure should be developed that assures AIDS education at the earliest possible time.
4. The Sheriff should report to the Board on his efforts to eliminate IV drug abuse, tattooing and rape in the jails.

5. An appropriate AIDS protocol should be issued for the Women's Detention Center.

6. Condoms should be available to inmates.

7. Plans to house HIV antibody positive inmates in the isolation ward of the new jail should be overturned.

8. A special AIDS module should not be part of the Elmwood Master Plan.

9. Education of Sheriff's deputies on AIDS should be continued by the County Health Protection's AIDS Project. Jail administrative staff also should be educated about AIDS.

10. The Sheriff should obtain ongoing input from experts knowledgeable in Infection Control to develop AIDS programs and write AIDS policies.

11. The County Executive's Office should establish a mechanism to review procedures in all County correctional institutions to determine if policies regarding persons with AIDS, ARC or who are HIV antibody positive are medically appropriate and necessary.

Recommendation for Legislation Against Discrimination:

Because of the rise in the number of AIDS discrimination cases in other cities and the known cases of AIDS discrimination in Santa Clara County, the Task Force recommends that:

1. The Board of Supervisors should adopt an AIDS anti-discrimination ordinance affecting the areas of employment, housing, access to medical services, access to paramedical services, banking and lending institutions, and HIV testing.

Recommendations for the Future of the AIDS Community Task Force:

1. The existence of the Task Force should be extended for another year.

2. The Board of Supervisors should co-sponsor a public hearing on AIDS with the Task Force.

The Human Side of AIDS:

Behind each number of an AIDS case is a real person. The Task Force believes that it is important for the Board of Supervisors, county officials and the public to understand the effect AIDS has on people's lives. Therefore, we begin the report with three case histories of people who have been diagnosed with the disease.
First Local AIDS Report Issued

Over a year ago BAYMEC went before the Santa Clara County Board of Supervisors with its nine-point proposal to provide services to AIDS patients. Specifically, BAYMEC asked the supervisors to:

1. Allocate $60,000 in mental health contracts to the Aris Project for the remainder of Fiscal Year 1985-86; $120,000 for FY 1986-87.
2. Allocate funds to establish a residential care facility for chronically ill AIDS patients.
3. Establish a program to educate county employees who may work with AIDS patients, including deputy sheriffs, probation officers, social workers, and health department staff.
4. Create a Board-sponsored task force to assess needs and develop a comprehensive AIDS program for the county.
5. Allocate additional funds for education and educational materials targeted to high-risk groups.
6. Increase staff levels of the AIDS Project in order to provide more pro-active outreach to community groups.
7. Increase educational outreach to doctors, nurses and other health professionals to ensure high quality care in our county.
8. Utilize the county's ability to care for AIDS patients at Valley Medical Center.
9. Direct the Mental Health Department to establish a working relationship with the Aris Project to coordinate mental and emotional support for AIDS patients.

BAYMEC decided to bring forth its proposal when it became apparent that the County had no immediate plans to implement policies which dealt with the many issues surrounding AIDS. One by one, the nine points are being addressed. We hope that the remaining issues will be addressed after the recommendations of the Task Force have been approved by the Board of Supervisors.

The following contains all sections of the Task Force report except for the executive summary, case histories of three AIDS patients, footnotes, and attachments.

TASK FORCE MEMBERS

Ken Yeager, Chairperson
Treasurer, BAYMEC.
Wiggy Sivertsen, Vice Chair
San Jose State University.
President, BAYMEC.
John Ashworth
Councilman, Campbell.
Dr. Roger Kennedy
Kaiser Hospital, Santa Clara.
Co-Chairperson, Santa Clara County Medical AIDS Task Force.
Robert O. Mackler
Director, Hospital Conference of Santa Clara County.

Sharon Miller
Visiting Nurses Assoc.
Board of Directors, Aris.
Helen Miramontes
President, Cal. Nurses Assoc.
Board of Directors, ARIS.
Dr. David Stevens
Chief, Division Infectious Diseases, Valley Medical Center.
Professor of Medicine, Stanford Univ.
Ron Taylor,
Board of Directors, Aris.
Parole Agent, Calif. Youth Authority.
Board of Directors, BAYMEC.

The Task Force would like to thank the Health Protection AIDS Project, Valley Medical Center, Aris Project, BAYMEC, Department of Social Services, Terri Iacino, Arthur Morris, and Paul Morrell for their assistance in preparing this report.

March, 1987
Introduction

At the Board of Supervisors' meeting of January 14, 1986, representatives from the Bay Area Municipal Elections Committee (BAYMEC) presented a proposal concerning AIDS education and counseling services. Included in the proposal was a request for the establishment of a Board of Supervisors' Task Force on AIDS. In a February 11 response to BAYMEC's request, county staff recommended to the Board that the Task Force be formed. In the opinion of staff, such a task force should develop recommendations to 1) increase community awareness of AIDS; 2) that in worst cases estimate and eventually investigate the disease; and 3) stimulate practical, broad-based responses to the problems. A resolution establishing the Task Force was adopted and Board Chairwoman Susanne Wilson appointed Ken Yeager as chairman of the Task Force.

Representatives from BAYMEC met with the Health Department to decide membership of the Task Force. Membership was drawn from groups representing the community, health care providers, universities, and private industry. The first meeting of the Task Force was held April 17.

Regular monthly meetings followed. The Task Force was updated on activities of the County's inter-departmental AIDS Committee and the Santa Clara County Medical Society's AIDS Task Force. Statistics and information were requested from various agencies and discussions were held on services available to AIDS patients. Among other activities, the Task Force assisted in the development of a handbook specifying a policy for county employees on AIDS, investigated the Sheriff Department's Medical Units policy on AIDS, and reviewed the need and potential provisions of an ordinance outlawing discrimination against people with AIDS/ARC or suspected of having AIDS/ARC.

Late in the year, the Task Force broke into committees to research and write various portions of this report. The following is the result of our work.

Dr. Kenneth Kizer, director of the California Department of Health, said, "AIDS is rapidly emerging as the worst infectious disease epidemic of this century and probably will eventually rank as one of the worst epidemics of all time." We hope the Board of Supervisors will adopt our recommendations and use every available means to minimize the devastating impact that AIDS is having on our county.

Case Projections, Medical Costs and Medical Needs

We are now feeling the initial wave of what will be the worst epidemic ever experienced by the medical profession in the County. The federal Centers for Disease Control (CDC) project up to 270,000 cases in the U.S. by 1991. It is estimated that in 1991, 56,000 Americans will die of AIDS, which is more American deaths than occurred in the Vietnam War.

Estimates of cases, expenses, hospital days, etc. are subject to many possible variables, some of which can only be estimated. In this report, we have used the most accurate data available to us, and have cross-checked against estimates available from other sources. As data becomes more complete, the estimates can be revised by insertion of new variables.

Estimates of AIDS cases.

The County of Santa Clara had 183 cases as of 1/16/87 (Santa Clara Co. Health Dept.). Estimates of the projected annual rate of increase are 1.5- to 2-fold. This has resulted in estimates from various sources for 1991 in Santa Clara Co. of 1566-5760 cases. For the three preceding years the annual increase has been 2-fold. Factors that influence the projection include not only estimates of the rate of infection by the etiologic agent, human immunodeficiency virus (HIV), but the rates of conversion from subclinical infection to AIDS, movement of patients into and out of the county (e.g. to seek medical care here vs. elsewhere), and other factors. Heterosexual transmission is now a significant factor. The definition of AIDS is expanding, and the following numbers may be low for that reason. For this report, we have used an estimate of 1.8-fold for the annual rate of increase. This results in a projection of accumulated reported AIDS cases in the county as follows:

<table>
<thead>
<tr>
<th>Year</th>
<th>Cases</th>
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</thead>
<tbody>
<tr>
<td>1987</td>
<td>324</td>
</tr>
<tr>
<td>1988</td>
<td>583</td>
</tr>
<tr>
<td>1989</td>
<td>1048</td>
</tr>
<tr>
<td>1990</td>
<td>1888</td>
</tr>
<tr>
<td>1991</td>
<td>3398</td>
</tr>
</tbody>
</table>

Estimates of the life expectancy of AIDS patients from time of diagnosis to death range from nine months to three years. This will be influenced by the success of currently experimental therapies. We have used for our projections a life expectancy of two years. This results in the following estimate of living AIDS patients in the county requiring medical care:

<table>
<thead>
<tr>
<th>Year</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>1987</td>
<td>185</td>
</tr>
<tr>
<td>1988</td>
<td>319</td>
</tr>
<tr>
<td>1989</td>
<td>654</td>
</tr>
<tr>
<td>1990</td>
<td>1016</td>
</tr>
<tr>
<td>1991</td>
<td>1827</td>
</tr>
</tbody>
</table>

Estimates of ARC cases.

Current data suggests that there are 3 to 10 ARC (AIDS-related complex) patients per AIDS patient. ARC itself is a fatal condition only in that it progresses in many instances to AIDS (estimates of up to 70% over five years). Estimates of life expectancy of these patients are unavailable. ARC is not a reportable disease. For our projections, we have used an estimate of 6.5 ARC patients per AIDS patient. The number of estimated ARC patients in this county is:

<table>
<thead>
<tr>
<th>Year</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
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<td>1987</td>
<td>2106</td>
</tr>
<tr>
<td>1988</td>
<td>3790</td>
</tr>
<tr>
<td>1989</td>
<td>6819</td>
</tr>
<tr>
<td>1990</td>
<td>12272</td>
</tr>
<tr>
<td>1991</td>
<td>22087</td>
</tr>
</tbody>
</table>

These estimates of AIDS and ARC patients do not include asymptomatic persons infected with the HIV virus. Current estimates are that there are 75 HIV-infected persons per AIDS patient (300,000 Californians in 1986).
Estimate of medical costs.
The cost of hospitalization is the largest medical cost. Statistics available from other areas indicate that AIDS patients, on the average, require 2 to 3 hospitalizations per year. Estimates on the number of days of hospitalization vary from 69 days lifetime to more than 150 days. The amount of hospitalization required is subject to many variables, including availability of non-hospital care for sick and dying patients, success of experimental therapies in preventing the secondary complications (opportunistic infections and cancers) of AIDS that necessitate hospitalization, and other factors. In addition to hospital days, AIDS patients are estimated to require 20 outpatient visits/year. We estimate for purposes of this report that ARC patients require the same amount of out-patient care and no hospital care; we do know, however, that ARC patients are hospitalized for diagnostic work-up and therapy, but hospitalization data is not available for them.

For these calculations, we estimate an average of two hospital stays per year for the projected two year life span of an AIDS patient. Data on hospital charges in Santa Clara County for AIDS in the first half of 1986 show an average charge per stay of $17,718. This excludes physician fees. The average length of stay reported for January to March 1985 was 18.2. This stay declined to 11.5 days in June, 1986. AIDS patients require relatively more intensive care unit (ICU) days than the average patient, and ICU days are more expensive than average hospital days.

To this we have added physician charges in hospital. These patients are complex cases, with multi-organ involvement with opportunistic infections or cancer, and require attention from several specialists and generalists. We have estimated an average total physician charge of $61/hospital day.

Using 1986 actual costs for hospitalization, estimates of physician fees and assuming a 5% annual inflation estimate, the hospitalization charges/patient/year estimates for the county are:

- 1987 - $38,682
- 1988 - $40,616
- 1989 - $42,647
- 1990 - $44,749
- 1991 - $47,018

For 1987, the charge/hospitalization would be $19,341/hospitalization. It should be pointed out that alternatives to hospital care (including nursing homes, hospice for AIDS patients, and extensive supportive community resources) do not presently exist in Santa Clara County. Using the estimates of living AIDS patients above and the estimated inflation rate, the estimates of annual hospitalization charges are:

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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS patients</td>
<td>185</td>
<td>319</td>
<td>564</td>
<td>1016</td>
<td>1827</td>
</tr>
<tr>
<td>$7,156,000</td>
<td>$12,957,000</td>
<td>$24,053,000</td>
<td>$45,495,000</td>
<td>$85,902,000</td>
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</table>

Each outpatient visit has been estimated at $100. Given 20 visits/patient/year, the numbers of living AIDS and ARC patients estimated above, and a 5% inflation rate, the estimated annual outpatient medical costs are:

<table>
<thead>
<tr>
<th>Year</th>
<th>AIDS</th>
<th>ARC</th>
</tr>
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<tbody>
<tr>
<td>1987</td>
<td>$370,000</td>
<td>$4,212,000</td>
</tr>
<tr>
<td>1988</td>
<td>$670,900</td>
<td>$7,959,000</td>
</tr>
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<td>1989</td>
<td>$1,244,000</td>
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<tr>
<td>1990</td>
<td>$2,352,000</td>
<td>$28,410,000</td>
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<tr>
<td>1991</td>
<td>$4,441,437</td>
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</table>

The lifetime medical costs, hospital and outpatient, using these estimates for an AIDS patient living the two years 1987-88 is $82,000. Thus, the total estimated annual medical expenditure, hospital and non-hospital, for AIDS and ARC patients is:

- 1987 - $11,738,000
- 1988 - $21,586,000
- 1989 - $40,333,000
- 1990 - $76,257,000
- 1991 - $144,036,000

Projections using higher estimates of the number of AIDS patients in 1991 suggest medical care costs could be as high as $265 million to $432 million in Santa Clara County for AIDS alone in 1991.

Who will pay these costs?

Preliminary data from 1985 in Santa Clara County (Hospital Conference of Santa Clara County) indicated the following hospitalization payment sources (sample size, 72):

- 30% HMOs (including Kaiser)
- 8% Blue Cross
- 25% Other commercial insurance
- 22% MediCal
- 3% Medicare
- 1% Title V
- 10% No insurance - (includes free, research funds, medically indigent adult, self pay.)

At present, the MediCal program has made AIDS automatically eligible for support.

What will be needed for the medical care of these patients?

Assuming that 6.3% of the AIDS population will be in the hospital at any one time, the number of acute care beds needed daily for AIDS patients will be:

- 1987 - 12
- 1988 - 20
- 1989 - 36
- 1990 - 64
- 1991 - 115

Based on current empty private beds in the county, and assuming that these beds are not converted to other uses, there would appear to be no need for new construction during this time period. It may be desirable for several of the private hospitals with significant unused bed capacity to develop AIDS wards in their facilities. If SCVMC continues to run close to capacity, new construction or conversion of other units to inpatient beds may be needed to accommodate its share of the population. Available capacity in private and public hospitals will have to be re-examined in
several years to make projections for five years further, to 1996.

Chronic Care Beds
Approximately 360 beds will be required by 1991, divided between skilled nursing facilities and hospice beds. Adequate long-term care facilities could reduce the need for acute care beds and provide care in an optimal setting. It is quite clear that the bed availability to provide this need is unavailable at this time, and a major effort will have to be mounted to provide for this need.

Outpatient Facilities
It would be desirable to develop AIDS clinics in the private sector where specially trained nurses could do a substantial portion of the monitoring. It is also desirable to develop outpatient facilities for intravenous drug therapy, which might be necessary for many patients on a weekly basis.

Home Care and Social Services
It is possible that home health care would be the appropriate level of service for AIDS patients for an average of four weeks during their illness. This would include completion of initial therapy for infections and possibly terminal in-house hospice-type care. This will vary extensively with different groups and with individual patients. Estimates of personnel needs for these areas are as follows: One social worker for every 60-80 patients; one home health nurse for every 60-80 patients.

Data on home care costs to AIDS patients is not readily available. Medicare, Medi-Cal, and some private insurance companies pay for intermittent home care services. Most agencies require demonstration of need for ongoing skilled care, such as nursing, before they will pay for supportive or custodial care. Few private insurance policies cover 24-hour care in the home. A minimum charges for intermittent nursing care, home health aids and medical social work may be $1,000. The average duration of home care services following an acute hospitalization may be two months.

Public Hospital Needs
Medical experts estimate that one-third of the county's AIDS patients may become the responsibility of SCVMC. In 1985, when 90 accumulated cases had been reported in the county, 28 patients were seen in consultation by the SCVMC Infectious Disease Service, and others by other services, including Dermatology, Pulmonary, and General Medical Services. Alameda County (5 Year Plan Report) estimates that 30% of its patients will be cared for through county governmental facilities. By 1/16/87, 22% of the AIDS patients reported to the Health Department had been admitted first by SCVMC; the number of SCVMC responsible patients may rise as patients are referred from hospitals unaccustomed to caring for AIDS patients, from Stanford University Hospital for patients exiting special experimental protocols and not receiving ongoing care there, and from any facility if and when a patient's payment sources run out.

Specific program development to care for SCVMC AIDS patients has been small to date, and support for it has been small by comparison with the current and anticipated needs, and in comparison with a more appropriate level of support and effort expended in some other programs in the County.

To date, the Board has budgeted one additional non-physician "clinical coordinator" position to coordinate SCVMC's AIDS programs. Consistent with its mission to provide "state of the art" care to County-responsible patients, and its mission as an academic medical center, program development at SCVMC should be expanded, particularly with specialist physician(s), and should be more centralized. A supervising specialist physician could be responsible for development of funding proposals and grant writing, preparation of statistical reports, overseeing special studies, and general oversight of the entire program.

Physicians leading the AIDS effort must have the background to travel with the advancing edge of medical research, as this is a most active area of medical investigation at this time, and for the foreseeable future. Building on existing interest and expertise in opportunistic infections and cancers, specialized protocols, cooperation with Stanford Medical School and liaison with the gay community, SCVMC could be a local resource for the medical community and complement Stanford Hospital, particularly in the southern County, in attracting referrals for consultation, protocols, or therapy. An AIDS clinic, the first in the County for ongoing care (as distinct from screening or exclusively research purposes) should be promoted. The supervising physician described would supervise the aforementioned "clinical coordinator." The coordinator would: assist with statistics, do obligatory reporting to public health agencies, be a liaison with the health department, work with outpatient providers to facilitate hospital admissions and discharge back to outpatient care, coordinate transfers from acute to long term care, coordinate supportive services on discharge and hospice care when needed, assist with experimental protocols, work with family and friends of patients, ease the inevitable glitches in the system, triage incoming queries, and assist in education staff about epidemiological problems these patients may engender.

An outreach program as described could also assist other County agencies with medical aspects of their AIDS-related problems, e.g. the Sheriff's Department as described in other parts of this report. It also would complement ongoing educational and epidemiological efforts of the Health Department.

Need for Research
A long-term answer to the problems posed by AIDS lies in research. Research by County employees and other persons in the county should be encouraged at all levels of government, and by private and corporate support. A relatively small research investment in the prevention and treatment of HIV infection, and of opportunistic infections and cancers, and in more effective health care delivery, testing and education, could have a large impact on the staggering costs of the future medical care of AIDS patients. Most important, it could have an impact on the survival of Santa Clara County residents, and on the suffering of AIDS victims.
Recommendations

1. The County should expand its resources at SCVMC. This would include development of a specialized AIDS care unit and clinic, and the recruitment of a specially trained staff.

2. The County should address the lack of availability in the community for health care resources needed after discharge from acute hospital care. The priorities are skilled nursing facilities, home health care services, and hospice services.

3. With the guidance of the Hospital Conference and the Santa Clara Valley Medical Center, each hospital should develop policies to facilitate care of AIDS patients. They should be able to identify physicians who are knowledgeable about AIDS treatment and are familiar with community support services.

4. Research by County employees and other persons in the county should be encouraged at all levels of government, and by private and corporate support.

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**Education**

Community education about AIDS must address epidemiology, treatment and prevention. Researchers are working on treatment protocols and a vaccine, but the results are probably years away. Education, though expensive and time consuming, is therefore the only viable approach to prevent the number of AIDS cases from continuing to nearly double annually in the years ahead. Dr. Constance Wofsy of San Francisco General Hospital states that it takes a minimum of five educational exposures (don't understand, don't believe, beginning to believe, it's a problem for others, they're talking about me) before an individual has an understanding of AIDS, its causes, epidemiology and prevention.

It is estimated that by the year 1991, there will be 3398 cases of AIDS in the county. According to James Curran, M.D., at the CDC in Atlanta, three-fourths of those who will develop AIDS by 1991 are already infected. Education must be intensified and the media utilized to the fullest if non-infected people are to escape infection. Educational programs must be directed toward all groups in the population regardless of gender, ethnic background, race, age, religion, or sexual orientation.

**Background**

AIDS education and prevention campaigns began as early as 1983 by a private non-profit organization called the Santa Clara County AIDS/KS Foundation. The Foundation provided education and support services to people with AIDS and to those at risk for AIDS. The Santa Clara County Health Department worked closely with the AIDS/KS Foundation to provide educational programs to people at risk for AIDS, and to individuals who would be providing social and health care services to them. In mid-1984, the Foundation's operations were transferred to the Health Department to supplement its AIDS Project.

The Health Department's AIDS Project is part of the County's Health Protection Division. AIDS education is provided through lectures, a telephone hotline, written materials, and through radio/TV outreach. Education is also provided by the VD/STD Clinic, the AIDS Screening Clinic, and HIV antibody alternative test sites. As the community's awareness of AIDS has increased, so have requests for services. This has placed great strain on existing programs. Although the programs are respected and well-received, the Health Department is unable to meet the growing needs of a county of almost 1.5 million people due to the lack of adequate funding for educational materials and the lack of sufficient staff—essentially three individuals. The Board of Supervisors allocated funds in June, 1986 to hire a Spanish-speaking health educator to provide education and training to the Hispanic population. It is expected that the staff person will be hired soon.

**Need for Education**

Action must be taken immediately to curb the increase in the number of individuals infected with the AIDS virus. The Task Force, along with the Health Protection Division and leading AIDS experts have identified the following immediate needs for AIDS education and prevention.

A. **Educational materials.**

A wide variety of educational materials must be developed to reach the entire community. This can be done in creative ways through an extensive AIDS education campaign. More printed materials must be purchased and/or developed. The AIDS Project produced a general informational AIDS pamphlet, but printing was limited to several thousand copies because of the limited funds from the existing state grant. Requests from the community for the pamphlets far exceeded the supply. Also, television and radio promotions must be developed, and handout racks with printed information must be available at hospitals, pharmacies, libraries, medical offices, etc. Educational materials and programs are needed for specified groups, such as Latinos, Blacks, Asians, American Indians, women, and youth.

B. **Training materials.**

One major focus of AIDS educators should be to train people in the community to assist in AIDS education. This was done, for example, by the Santa Clara County Medical Society and the Health Department in the recent "No On 64" campaign. Training materials should be available immediately so that more community educators will have enough basic AIDS information to educate others. Video tapes, slide shows and training manuals should be developed and distributed to these educators. Presently, the Health Department's AIDS Project is organizing a core group of public health nurses who have been educated about AIDS issues and resources. These AIDS resource nurses will work throughout the community.

C. **Substance Abuse Education.**

Due to the growing evidence that AIDS is increasing among substance abusers, and that AIDS is spreading through this group to the community at large, educational outreach must be provided to this population. Existing programs and materials will have to be modified and adapted to meet the special educational needs of drug and alcohol abusers. Educators, counselors and social workers need training about AIDS to overcome their own fears and anxieties. Education must begin immediately with substance
Special Report

AIDS education will also ease fears when a co-worker is diagnosed with AIDS. This is especially important in light of the recent decision by the California Fair Employment and Housing Commission to ban job discrimination against AIDS victims.

The County of Santa Clara should be commended for its decision to publish and distribute to all County employees an AIDS handbook which discusses AIDS and ways to avoid infection, and outlines the rights of workers who are diagnosed with AIDS. Universities such as Stanford and San Jose State have published or will soon publish similar handbooks. The Business Leadership Task Force of the Bay Area—which includes Bank of America Corp., Chevron Corp., Pacific Telesis, Mervyn's, AT&T, and Wells Fargo—recently sponsored a project to develop extensive guidelines on how to handle AIDS in the workplace.

The local media should also become more active in producing and distributing AIDS information and education materials. As an example of what can be done, the Los Angeles Times recently reproduced and inserted the U.S. Surgeon General's Report on AIDS in a Sunday edition. The San Jose Mercury and other local newspapers should undertake similar creative projects, as should local television and radio stations.

Recommendations

1. The following projects and personnel should be funded in fiscal year 1987-1988:
   a. A wide-range of printed and audio/visual materials. Included should be materials targeted to Latinos, Blacks, Asians, American Indians, women, and youth.
   b. An additional health educator to reach the substance abuse population.
   c. An additional health educator to develop educational programs, do outreach to schools, and to assist in the presentation of educational programs in the schools.
   d. An additional health educator to develop and deliver programs on women's issues.
   e. An AIDS Clinical Nurse Specialist to provide expertise to clinics currently operated by the Santa Clara County Health Department.

2. Additional funds should be allocated in future years to produce and update AIDS educational materials and to hire more personnel.

3. The Board should work in a collaborative manner with external funding sources, groups and organizations to provide the widest possible distribution and development of educational materials.

Page 6
Housing Needs

When BAYMEC appeared before the Board of Supervisors in January, 1986, included in its proposals was the allocation of funds to establish a residential care facility for chronically ill AIDS patients. In a response by the Director of Public Health, the Board was informed: "Experience in San Francisco and New York suggests that these services will be needed. Last week the Health Department AIDS Project received 4-5 inquiries about residential care. This is a problem in that the county's residential care spaces are already stretched to the limit; and the fact that AIDS is listed as a communicable disease means that some skilled nursing facilities will not consider accepting AIDS patients. The AIDS Task Force should evaluate these special needs."

The housing needs of PWAs are similar to those with other debilitating diseases. An AIDS/ARC patient's housing needs may change over time from a completely independent living situation to one requiring total caretaking, or it may fluctuate. Some PWAs may need assistance with the activities of daily living and others may not, or they may have family and/or friends providing support. If PWAs develop organic dementia complications, they may require a much more structured environment and closer monitoring. Presently, there are no specific facilities in Santa Clara County designated for PWAs.

As stated in the medical section of this report, approximately 360 beds will be required by 1991, divided between skilled nursing facilities and hospice beds. Adequate long-term care facilities could reduce somewhat the need for acute care beds and certainly provide care in an optimal setting. It appears quite clear that the bed availability to provide this need is unavailable at this time, and a major effort will have to be mounted to provide for this need.

Findings:

The housing needs of AIDS/ARC patients will increase as previously self-sufficient individuals are no longer able to work and take care of themselves. Many PWAs will require assistance in daily living activities, such as dressing, eating, and bathing. The need for assistance will increase as the number of AIDS cases increase. Presently, there is no plan to provide home care to PWAs.

In cities with increasing numbers of AIDS/ARC cases, there are many reports of eviction by landlords who are frightened of and unknowledgeable about AIDS and its transmissibility.

People with AIDS/ARC will have need for some or all of the following types of services:

- Day Center—a non-residential place for leisure activity for people with AIDS/ARC to relieve social isolation.
- Low Income Housing.
- Independent Living Facilities.
- Residential Care Facilities.
- Respite Care—a place where the patient can get proper care while at the same time giving the regular caretakers a rest from day-to-day responsibilities.
- Hospice Care—for pain management, medical stabilization and terminal care.
- Skilled Nursing Care.

- Day Care—a place where neuropsychiatric patients can receive care designed to meet their specific needs.

People providing these services—both County employees and contractors—need to be educated about AIDS/ARC so that they will be able to provide proper service. There is a history in the county of certain non-profit organizations that regularly provide such services denying them to AIDS/ARC patients. County contracts with contractors do not now require that they service people with AIDS/ARC.

The increase in the number of AIDS/ARC cases will burden the existing facilities which provide housing assistance. It may become necessary to provide additional facilities in the future. Currently, there are no plans to do so.

Recommendations:

1. The Board should direct the Administration and County Counsel to include language in all contracts to require that service be not denied to individuals with AIDS/ARC when providing the following:
   - Day Center activities
   - Low income housing
   - Independent living services
   - Residential care services
   - Respite care
   - Hospice care
   - Skilled nursing care
   - Day care

2. The Board should direct the County Executive to report back within 90 days on the need through 1991 for additional housing facilities and services that may be necessary for people with AIDS/ARC.

AIDS Policies In The Jails

Background:

The protocol to isolate AIDS, ARC and HIV antibody positive inmates and to take medically unnecessary measures during their incarceration was brought to the attention of a member of our Task Force in early September. On October 16, a front-page article about the protocol appeared in the San Jose Mercury. Because the announced protocol differed from policies in most state and federal prisons (according to a national study for the federal Department of Justice), the Task Force reviewed the rationale for the protocol. The medical director of the Sheriff's Department, Dr. Eagle Sloan, and the Assistant Sheriff of the Bureau of Custody Wes Johnson, made presentations to the Task Force.

From the presentations, the Task Force learned that there was a general panic among the deputies about AIDS. Furthermore, prior to the writing of the protocol the Sheriff's Department did not want to house AIDS, ARC or HIV antibody positive inmates in the jail, but wanted to transfer them to VMC. Because it is very expensive to provide custodial care at VMC for prisoners, this was not a viable solution. The Infection Control Unit at VMC did make available to the jail physician copies of policies developed at VMC for the hospital. These were used in
part to develop the Nursing Services' current protocol on AIDS for the Sheriff's Department Medical Units.

Findings
The current protocol
The Task Force found two major problems with the protocol.
1. No distinction is made between an inmate with
symptomatic AIDS or ARC and an inmate who is HIV
antibody positive or with AIDS/ARC in remission.
Inmates with symptomatic AIDS or ARC are, by definition, ill. Their immune system is deficient, which makes them vulnerable to a variety of opportunistic diseases. For this and other health reasons, they require special medical attention. To the knowledge of the Task Force, there have been no cases to-date of a male inmate with AIDS or ARC booked into the county jail. Should such cases occur in the future, the jail physician might advise hospitalization depending on severity of the illness. Because it is unlikely that an AIDS or ARC patient would be housed in the jail, the policy is only relevant to HIV antibody positive inmates.

By being placed in medical isolation, HIV antibody positive inmates are grouped in the same category as inmates whose highly contagious diseases make it impossible for them to participate in such programs as work furlough and trustships. In addition, they are subject to regulations designed for inmates with contagious diseases, such as Hepatitis A and measles, and they must speak through a plastic-wrapped telephone receiver, eat on disposable plates, and have their clothes marked "contaminated."

These procedures are not only medically unnecessary and personally humiliating; they also confuse the distinction between a patient who is HIV antibody positive and one who actually has AIDS or ARC, and further the notion that AIDS is casually transmitted. The AIDS virus is very fragile, and can only be transmitted through direct blood-to-blood contact or by certain sexual practices.

It should be noted that the protocol is not applicable to the Women's Detention Facility at Elmhurst. The women's jail does not have an isolation ward, only a "sick bay." One woman who requested to be tested for the AIDS antibody was discovered to have ARC. Dr. Sloan asked that a judge dismiss her case. The request was granted. The Task Force believes that the jail physician and the Sheriff, upon reviewing the current protocol, should issue an appropriate protocol for the Women's Detention Center.

As stated in the current protocol, one of its purposes is to "provide an optimal level of care to immunocompromised patients." However, people who are HIV antibody positive are not immunocompromised. While it is important to use infection control procedures when dealing with the blood or body fluids of any individual, there is no medically supportive reason to treat an HIV antibody positive inmate differently from anyone else in the general population. Correctly, the protocol does not make reference to a physician's need to advise hospitalization for HIV antibody positive inmates.

In testimony before the Task Force, speakers stated that the purpose of the protocol is to protect the inmate. It seems, however, that the protocol's purpose is to (falsely) protect the jail staff and other inmates. This makes the patient a "villain." Such a philosophy is clearly wrong.

2. The Nursing Services' protocol differs from that of VMC Infection Control's protocol.

The VMC Infection Control Manual does not call for isolation of AIDS, ARC or HIV antibody positive patients. It does state that a private room should be used until assessment of the patient indicates lesser precautions are adequate. Respiratory or Strict Isolation can be required if appropriate. A cooperative, non-coughing patient without diarrhea may have a roommate if the roommate is not an immunocompromised host and does not have infection. Masks, gloves, gowns, and/or protective eyewear should be worn where there is close, sustained contact with a patient with any disease transmissible by blood or other body fluids.

An HIV antibody positive inmate who is not otherwise ill does not need medical attention. The chance of a sheriff deputing coming into contact with the inmate's blood or other body fluids is no greater than with any other inmate. Dr. David Stevens, head of the Infection Control Unit at VMC and a member of the Task Force stated that the AIDS policy for the jail "does not represent what we do in our institution. We would not recommend and never recommended such a policy."

Testing
Testing of inmates for the HIV antibody is done through the Health Department and is strictly voluntary, as is mandated by California law. Dr. Sloan counsels all those requesting the test or information about its implications. Approximately 50 percent of the inmates who initially request the HIV test change their minds. The Task Force supports this procedure. After one year, 24 inmates have been tested, four of whom were found to be HIV antibody positive. Dr. Sloan ordered each of them to medical isolation.

Although test results are confidential under California law, as soon as an inmate is placed in medical isolation, he is assumed to have AIDS by both the jail staff and the prison population. In practice, therefore, there is no confidentiality.

High-Risk Behavior
From the presentations, the Task Force learned that IV drug abuse is prevalent. This is evident by the large confiscations of drug paraphernalia found during weekly shakedowns. Tattooing with unclean needles is a common practice. Although we know that forced homosexual rape occurs, no information was provided on its frequency.

From the information obtained by the Task Force, it appears that the entire jail population is at risk for exposure to the AIDS virus. Yet, AIDS education is not available to inmates. Condoms are considered contraband by the Sheriff's Department and therefore unavailable. Although inmates are in constant jeopardy of exposure to the AIDS virus and of potentially infecting others when released, no preventative measures have been taken.

Education
AIDS education is not mandatory, yet information can and should be available during the booking process and during incarceration. While the Task Force understands the difficulties inherent in educating people who have little regard for society's rules and regulations, we do not believe
1. Expressed needs in El Dorado (cont.)

   e. A regional inter-county coalition could be formed to assist patients who need specialized care. Patients requiring chemotherapy or specialized treatment should be referred to Sacramento. The Department of Mental Health could contract with an agency to provide care for people with dementia from this county.

   f. Residential programs for IV drug users with HIV infection need to be established (possibly in South Lake Tahoe).

   g. Expansion of home health and attendant care by existing local providers.

   h. As services expand in El Dorado county, there will need to be a clear policy established on the treatment people with HIV infection from Nevada.

G. Sacramento

After looking at El Dorado county which is dependent on Sacramento for education and treatment, we would like to quickly review the regional treatment programs for nine counties around Sacramento.

Fifty percent of AIDS/ARC patients are being treated at UC Davis AIDS Clinic, while 30% are being treated at Mercy Hospital by one private physician. Kaiser Permanente treats 15% and the others are treated at local hospitals such as Sutter. The service area extends into the northern counties including El Dorado and incorporates the Reading/Chico area with Sonora. Some physician calls are 150 miles from the hospital. A Mayors Task Force has recently completed a local survey and recommendations (August 1986, enclosed).

A research and treatment group (UC Davis is part of the 5 campus clinical drug trials) meets every 2 months. There are 2 to 3 physicians who are presently overwhelmed by the amount of administrative work associated with these clinical drug trials.

A physician at UC Davis reported 600 new infections in the county over an 18 month period, (324 gay men and 275 IV drug users). Drug users with HIV infection were being served through the Aquarian Program although it was strongly felt the amount of money being spent on blood screening ($14,000 per HIV infection) was disproportionately high to the levels of spending for both treatment and prevention with known risk groups where the infection rate was about five percent each year. There was also a two to three week waiting time for anonymous blood testing in the county.

The average census at UC Davis (from November) was 5 patients with AIDS with projections that in three to five years AIDS patients could will represent 20% of the inpatient population.
it is impossible to convey the dangers of high-risk behavior to the jail population. There is no other alternative. The Sheriff’s Department must formulate an effective AIDS education program for its inmates or else take responsibility for the fiscal, medical, and moral consequences of the needless infection of an entire group of people with AIDS. Education of prisoners also provides an opportunity to reach an at-risk segment of the population which is difficult to reach on the streets and likely to spread the disease into the community at-large.

San Francisco, which like Santa Cruz County, does not isolate its prisoners, has set up an AIDS education program. Santa Clara County could learn much from San Francisco’s experiences as well as from other prison systems with similar programs.

Staff training

The Task Force was greatly concerned when Assistant Sheriff Wes Johnson stated that the jail staff was not being educated about AIDS. He said the reason for this was that no one in the state was qualified to conduct such a training. It was pointed out to Mr. Johnson by Task Force members that the County Health Department provided training to deputies last year, and is willing to do so again this year. According to Public Health employees, jail administrative staff have not participated in the training program.

The new jail

Construction of the new jail is expected to be completed in December, 1987. Wes Johnson stated that people with AIDS will be housed in single cells in the medical unit.

If, in the future, a person with AIDS or ARC is booked into the main jail, it might be appropriate to house him in the medical ward. However, for reasons previously stated in this report, an HIV antibody positive inmate should not be placed in the ward. We have concerns that this will occur.

The Task Force has learned from the County’s program manager for the Elmwood Master Plan that Dr. Sloan has proposed single-cell availability for AIDS inmates and a possible AIDS housing module as part of the Master Plan. A separate module would be medically unnecessary, poor use of valuable space, and a waste of taxpayers’ money. We strongly oppose such a plan.

Recommendations

1. The policy to put HIV antibody positive inmates in maximum-security medical isolation should be overturned.
2. HIV antibody positive inmates should be granted the same privileges as other inmates, such as full participation in work furlough programs and trusteeships.
3. Ongoing AIDS education should be made available to all inmates, and be mandated for male and female inmates who have been sentenced. A procedure should be developed that assures AIDS education at the earliest possible time.
4. The Sheriff should report to the Board on his efforts to eliminate IV drug abuse, tattooing and rape in the jails.
5. An appropriate AIDS protocol should be issued for the Women’s Detention Center.
6. Condoms should be available to inmates.
7. Plans to house HIV antibody positive inmates in the isolation ward of the new jail should be overturned.
8. A special AIDS module should not be part of the Elmwood Master Plan.
9. Education of sheriff deputies on AIDS should be continued by the County Health Department AIDS Project. Jail administrative staff also should be educated on AIDS.
10. The Sheriff should obtain ongoing input from experts knowledgeable in Infection Control to develop AIDS programs and write AIDS policies.
11. The County Executive’s Office should establish a mechanism to review procedures in all county correctional institutions to determine if policies regarding persons with AIDS, ARC or who are HIV antibody positive are medically appropriate and necessary.

County Legislation

Discrimination in Santa Clara County

Because AIDS is not spread by casual contact, a person with AIDS or ARC poses no health threat to the general public. However, in Santa Clara County there are reports that certain services have been unnecessarily denied to patients with AIDS. Based on our projections, the number of AIDS cases in Santa Clara County will increase almost geometrically over the next five years. With increasing numbers of individuals with AIDS and ARC, increased cases of discrimination are anticipated.

The Task Force does not know the full extent of current discrimination. We do know that certain publicly-supported groups turn away AIDS patients. In the past, the Center For Living With Dying, a United Way agency, refused to provide services to AIDS patients. To our knowledge, all long-term care facilities, i.e. nursing homes and convalescent hospitals, have not allowed admission to AIDS patients. While paramedic services appear to be available, AIDS patients are charged an additional fee of $50 to sterilize the ambulance after usage. Similar fees are not applied to other patients. The Sheriff’s Department routinely isolates individuals testing HIV positive.

Families and friends of AIDS patients also face discrimination. Helen Miramontes, President of the California Nurses Association and a member of the Task Force, reported a case in Santa Clara County where the fear of AIDS led one employer to fire the husband of an AIDS patient.

Unfortunately, certain political and religious groups have taken advantage of the AIDS epidemic and have morally condemned the victims. Without the force of law to stop this bigotry, these individuals can perpetuate the myth that AIDS patients must be separated from the community. Fortunately, the defeat of the LaRouche-sponsored AIDS initiative indicates that a large majority of the voters in Santa Clara County believe that AIDS patients do not pose an undue threat to the community.

The State and other cities

As evidenced by reports in San Francisco, Los Angeles, New York, and other cities, AIDS discrimination exists in
STAGES OF DISABILITY

<table>
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<tr>
<th>Stage Description</th>
<th>AIDS in Community</th>
<th>AIDS in Hospital</th>
<th>All AIDS</th>
<th>Severe ARC</th>
<th>AIDS + ARC</th>
<th>Total AIDS and ARCs by 1990</th>
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<td>0</td>
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<td>170</td>
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E. Orange County

In the past twelve months the Orange County Health Department has shown active leadership in the planning and coordination of AIDS related services through the local health officer (LHO) and the hiring of an AIDS Coordinator. The LHO is convening a 15 member Advisory Group on AIDS who will assist him with recommendations and policy decisions as to the future of AIDS services. Although there are 30 - 40 physicians in the county who are treating AIDS patients, the majority of cases are seen by 10 physicians. Fourteen hospitals in the county have treated AIDS patients with 17% of patients in Laguna Beach and 50% in the Anaheim/Newport Beach area. The two main AIDS centers in Orange County are the University of California, Irvine (UCI) and Hoag Hospital in Newport Beach. UCI is also involved in the statewide 5 campus study. There is no figure available on the number of dentists caring for people with AIDS/ARC.

The principal outpatient facility is the County AIDS Clinic which provides anonymous blood and diagnostic testing, and contact investigation on a voluntary basis. The anonymous testing is providing on an immediate walk in basis with no waiting. Another interesting service in Orange County is available for medical examinations 5 days and one evening per week for people who are seropositive.

Hospice and home health care are provided by the county or the Visiting Nurses Association and Hospice of Orange County. There is no skilled nursing facility in Orange County. The Catholic Diocese of Orange is exploring the possibility of providing a shelter/hospice facility with support from the local health officer.

The County Drug Rehabilitation Program provides HIV Anonymous testing and has admitted a few patients into the Methadone program. Testing is also being carried out in the county jails and among prostitutes on a voluntary basis. 10 patients who have AIDS are IV drug users who need specialized residential treatment services.

The County AIDS Clinic and The AIDS Service Foundation provide case management for clients. The AIDS Service Foundation has two full time staff and 100 volunteers (trained in the Shanti emotional support model). They are serving 105 active clients. Volunteers are usually referred by gay identified resources. One staff person administers the programs while the other recruits, trains, supports, and schedules volunteers. Volunteers provide 100 hours of service each week approximately. There is a bimonthly support group and a turn over of volunteers every 6 months (the minimum commitment commitment of the agency). There are forty emotional support volunteers or buddies, while three volunteers link the hospitals patients with the Foundation through initial intakes and visiting. Liaison with the local Department of Social
E. Orange County (cont.)

Service is good, with the Foundation acknowledged as the principal client Advocacy Group for people with AIDS/ARC. The Social Services Department has a designated AIDS problem staff person for problem solving.

A network of volunteer clergy are providing another important community resource. The 'AMEN' clergy group are often called in to assist in crisis intervention, often because of lack of staff. The Aids Service Foundation also provides a 6 bed shelter facility for PWA's/ARC in Tustin, charging $50 per month from each client. Fifty clients have also had their apartment rent subsidized up to $1,200.

There is an existing coalition of AIDS Service Providers to identify Orange County's needs and networks. The local health officer is developing a regional network of other health officers in San Bernardino, Riverside, Los Angeles, and Ventura counties for regional planning purposes. Client complaints come often to the providers through the local Gay and Lesbian Community Center, where most of the AIDS education and prevention programs are focused.

Expressed unmet needs in Orange County are:

(1) The need for a coordinated case management structure to combine resources, client advocacy, evaluating client alternatives and overall data collection useful to future planning.

(2) The need for a skilled nursing facility. It has been difficult to encourage the existing private health system in Orange County to develop AIDS-related services.

(3) A continuum of residential needs from shared housing through Shanti-like homes to residential hospice care is needed.

(4) Specialized facilities for IV drug users who have AIDS e.g. residential treatment programs.

(5) A liaison staff person for the Orange County religious community which has many underutilized resources i.e. shelter, food programs, hospitals, advocacy and volunteer pools.

(6) A program to develop a mental health program for people with HIV infection, AIDS, ARC, people with dementia, caregivers and loved ones.

F. El Dorado County

This county has two distinct communities with their own service networks and AIDS related concerns in South Lake Tahoe
and the Tahoe Basin. Although South Lake Tahoe has a higher proportion of IV drug users, prostitutes and these communities are often difficult to reach gay and bisexual men. The gay community in this area is very discreet (the local gay bar is not interested in developing AIDS education or AIDS related volunteer recruitment programs). In Placerville and the rest of the county, the service providers look to Sacramento for AIDS education, and specialized hospital services. These communities provide anonymous testing in South Lake Tahoe and Placerville and the local health officer has developed policy guidelines for schools, and a series of professional and public educational outreach campaigns on AIDS.

Barton Hospital in South Lake Tahoe has treated 15 patients with HIV related disorders in the past three years. Marshall Hospital in Placerville has also treated patients. Patients requiring more specialized care, such as chemotherapy, are sent to UC Davis, Reno, or Washo Medical Center. Outpatient care at the local hospitals is done through the emergency loan and all of the local care is provided by a few dedicated physicians. A recent local health department survey on AIDS for physicians and dentists was replaced by only 6 physicians (four of whom were from one practice) and an intern.

A local convalescent hospital was treating a 21 year old brain damaged male when staff discovered he had previously received infected blood. This was widely publicized in the local press and had no effect on the census of the hospital which is 96% full and was able to make the necessary changes in infection control and educate staff. The nursing home administrator was concerned about insurance and liability issues and requested clarification from the state licensing authority in Sacramento. After six months, the nursing home still has not received clarification.

This case study is interesting because it illustrates the need for policy changes and prompt attention with nursing facilities prepared to work with HIV infected patients. The major concern of the nursing home administrator was the low reimbursement rate of $46 per day through Medi-Cal when real costs of care were $70 per day. (increase is due to labor intensive infection control procedures)

Local home health care is provided through Barton Hospital while at Marshall Hospital the Visiting Nurses Association works with AIDS patients. Thirteen patients with ARC and three with AIDS were cared for at Barton. The local Social Service Department has provided limited attendant care and some local volunteers from the Sacramento AIDS Foundation have arrested people in need in their area.

There is no shelter facility for the homeless in the area and
F. El Dorado County (cont.)

in the opinion of the local people surveyed, the local community would support a Shanti-like house for people with HIV infection, (particularly the local Catholic community).

There is a board and care facility in South Lake Tahoe with 80 beds, two of which are reserved for hospice. Hospice in South Lake Tahoe has been in operation since 1980 and the volunteers have already worked with AIDS patients in Placerville. Placerville's local hospice organization has not worked with AIDS patients.

Many of the board and care facilities are very small serving up to six people. It may be possible to utilize one of these facilities in the coming months specifically for AIDS.

One of the people with AIDS in this area was an IV drug user. There are no residential services in the area to deal with AIDS and IV drug users, although there is a substance abuse treatment program in Tahoe and Truckee.

Patients with dementia will no longer be treated in the Placerville Convalescent home. El Dorado refers these people to Sacramento's Capitol City Convalescent Home (180 beds), which is now affiliated with Sutter Hospital.

There is a holding facility in the county which usually serves middle aged people in some form of emotional/mental crisis. It was described by locals as a very expensive way for the county to take care of people and was thought to be unsuitable for AIDS patients with dementia.

1. Expressed needs in El Dorado

a. Some cohesion and planning is needed between the different county, voluntary and private organizations already involved in AIDS service delivery. This could also include a support system for the care providers of this county.

b. Clarification and reform of reimbursement and insurance/and liability issues for skilled nursing facilities

c. Development of volunteers (recruitment training and supports) through the hospice movements in South Lake Tahoe and Placerville specifically to work with AIDS patients. (Sacramento AIDS Foundation could also be subcontracted to develop a volunteer program to work with these organizations)

d. Residential programs could be developed for people with HIV infection. This could range from a 6 bed board and care facility to a Shanti-type shared housing project. The local religious communities could be involved in these ventures.
G. Sacramento (cont.)

at UC Davis. Outpatients were being seen at the County Clinic which was serving a growing number of medically indigent adults (twenty-five patients with AIDS and 65 symptomatic).

A 1/2 time social worker position will be added to the existing staff to develop mental health programs for clients and staff. A one-half time alcohol and drug treatment counselor is also paid for by the hospital to work with HIV infected patients.

The Sacramento AIDS Foundation provides education, case management and client advocacy for the 77 clients in the nine county regions (fifty clients in Sacramento area and 27 beyond) with three full time staff and a part time psychiatric consultant who oversees one-hundred volunteers who are trained in the Shanti emotional support model.

Client information is computerized and links together the various social service and home health care agencies in the area. A group of local providers including the Administrator and Chaplain of Mercy Hospital have been meeting together to discuss the formation of a Shanti-type residence program. Mercy Hospital also provides home health care and will open a skilled nursing facility in early Fall with a percentage of beds being dedicated to people with AIDS/ARC.

Most of the AIDS related work and energy in Sacramento is developed through the 6000 volunteer hours of the Foundation. Various support groups, practical support and mental health services are provided by a close to 80 volunteer population which is in need of increased professional staffing. There is need for a mental health professional to work full time with this population. Care providers were critical of the county's ambivalence around AIDS treatment. An example of the lack of resources was when The Department of Psychology at UC Davis would only agree to work with patients if the Sacramento AIDS Foundation guaranteed finding a placement for the patient. Volunteers are dealing with suicidal clients without adequate professional support or training. The anonymous testing site post test counselling is provided by the Foundation's volunteer staff, although many of them are not mental health professionals. The county does not screen AIDS patients for dementia and this is becoming a problem for volunteers at the Foundation.

Because of the low rents in the Sacramento area, it is easier for someone on Social Security or Disability to be able to afford to remain in their own apartment. There is need for a "Coming Home" type hospice in Sacramento where people can die with appropriate support. The news of Mercy Hospital's skilled nursing facility opening in the next six months should be welcomed by discharge planners in the Sacramento hospitals and other service providers.
1. Expressed needs in Sacramento

   a. There is a need for expansion of the current levels of health care to reach rural areas. A mobile visiting team for patients at home consisting of nurses, social workers, attendants, physical and occupational therapists and psychiatric consultants could service outlying counties from a Sacramento base. (patients currently in need of this service: 2 in Yolo county, 10 in Stockton, 3 in Modesto, 6 in Chico, Yuba, 4 in Marysville, 2 in Auburn). Physicians are already doing home visits and could be part of this team.

   b. A comprehensive mental health program

   c. A range of residential and care facilities for detox, "Coming Home" hospice model, other services for people with AIDS, IV drug users with AIDS, people with dementia.

   d. An overall coordinator for AIDS services in the Sacramento region who would assist current providers to plan ahead and complete specific planning tasks.

   e. An overall case management system for the region.

   f. Clarification of the existing role and future role of UC Davis as the major provider of AIDS treatment to the Sacramento region.

   g. A skilled nursing facility (insurance, reimbursement and liability issues need to be addressed immediately by Medi-Cal and the licensing authorities to facilitate this goal).

   h. Please see recommendation in Mayors Task Force Report (following this page)....
Findings and Recommendations from the Mayor's Task Force on A.I.D.S. Sacramento California August 1986
August 11, 1986

The Honorable Anne Rudin
Mayor, City of Sacramento
915 I Street
Sacramento, California 95814

Dear Mayor Rudin:

Enclosed is the final report and recommendations of the AIDS Task Force.

On behalf of the AIDS Task Force I would like to thank you for the leadership and foresight you have provided this city in its struggle with the AIDS epidemic. Your willingness to act on this matter and to take the time to appoint a Task Force of experts should provide you and the City Council the direction necessary to maintain the progressive position Sacramento has established in dealing with AIDS. The efforts of the Task Force have resulted in a series of conclusions as a result of your charge. There are a number of steps in the enclosed document the City Council should consider adopting.

Thank you again for the opportunity to assist in this matter. The Task Force is prepared to support and assist in any continued efforts that may result from this report.

Very truly yours,

Kate Guzman, Chairperson
Mayor's AIDS Task Force

KG:1f

Enclosure
Acquired Immune Deficiency Syndrome (AIDS) has become a serious public health epidemic. In February of 1986, Mayor Anne Rudin formed an AIDS Task Force for the City of Sacramento. The charge of the Task Force was to provide clear objective information and recommendations to the City Council on how to deal with public policy issues created by this public health problem. The broad based 16 member Task Force was comprised of representatives of the community as indicated (see exhibit #1). The work of the Task Force was focused in four general areas: Prevention of Transmission; The Role of Education in Disease Prevention; Prevention of Discrimination Against Persons with AIDS and those at Risk for AIDS; and, Provision of Adequate Human Services to Persons with AIDS.

The Disease

Acquired Immune Deficiency Syndrome (AIDS) is caused by a Human Immunodeficiency Virus (HIV) that attacks and severely weakens a person's immune system. The virus was formally known as HTLV-III (human T-cell lymphotrophic virus, strain 3) or LAV (lymphadenopathy-associated virus) or ARC (AIDS-Related Complex) but will be referred to in this report as now internationally known Human Immunodeficiency Virus (HIV). Persons with the greatest immunodeficiency from HIV infection become susceptible to other infections from viruses, parasites, and fungi. An HIV infected individual may also develop one of several unusual cancers. Ultimately, both the secondary infections and cancers prove to be fatal. No AIDS patient has yet successfully regained immunocompetence spontaneously or by means of any therapeutic intervention.

Persons at Risk

In California 89% of all cases are amongst gay and bisexual men. The remainder of currently reported cases of AIDS are amongst IV drug users, recipients of blood / blood products, and sexual partners of all these groups of people. In Sacramento and nationwide, surveys of persons infected with HIV who are at high-risk for developing AIDS include:

<table>
<thead>
<tr>
<th>Category</th>
<th>Probability</th>
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<tbody>
<tr>
<td>Homosexual and bisexual men</td>
<td>(20-30%)</td>
</tr>
<tr>
<td>IV Drug Abusers</td>
<td>(1-5%)</td>
</tr>
<tr>
<td>Hemophiliacs</td>
<td>(40-60%)</td>
</tr>
<tr>
<td>Recipients of blood transfusions</td>
<td></td>
</tr>
<tr>
<td>between 1978 and mid 1985</td>
<td>(0.1%)</td>
</tr>
</tbody>
</table>

Though AIDS is primarily seen in these high-risk groups, it is important to remember that HIV can infect anyone under the appropriate circumstances. In Africa, HIV is transmitted primarily through heterosexual intercourse. By 1990 because of anticipated spread of HIV amongst IV drug users and their sexual partners, we expect to see an increasing number of people who will have acquired the disease through heterosexual contact.
Sexual activity of infected heterosexual drug users may pose increased risks to currently low risk populations. Infection of women will occur through intercourse with an infected male IV drug user and through women's use of IV drugs. Infected women may transmit the virus to their subsequent sexual partners and to their infants before or during birth. Bisexual men also spread the virus to women.

In Sacramento, a minority (perhaps 1-5%) of the IV drug users are currently infected with HIV however, in New York and New Jersey 50-80% of IV drug users carry HIV. In the east, rapid spread of HIV is thought to have occurred due to more frequent sharing of injection paraphernalia in "shooting galleries" where a needle and syringe may be used by dozens of individuals. In Sacramento, sharing appears to be done on a smaller scale, but is, nevertheless, sufficient to result in a relentless spread of the HIV virus in this population. The Task Force believes that it is only a matter of a few years before Sacramento experiences the same rise in the proportion of infected IV drug users and their sexual partners as has occurred in New York. This year antibodies to the HIV virus have been detected in at least 15 IV drug users and their sexual partners treated at the University of California Davis Medical Center. These IV drug users admit to sharing their paraphernalia with other individuals. The potential number of individuals who may become infected through needle sharing is in the thousands in Sacramento, and may result in a doubling of the number of infected Sacramento residents within 2-3 years.

Reported Cases

In Sacramento the first cases of AIDS were seen in the fall of 1981. It is estimated that there have been 70-80 cases of AIDS in Sacramento since 1981. One-half of these cases have been diagnosed in the last calendar year. Estimates of the actual number of people infected with HIV in the Sacramento area range from 1,500 to 6,000 depending on the method used for calculation. Estimates are that there will be 70-80 new AIDS cases in 1986, 140 cases in 1987, 280 cases in 1988, 560 cases in 1989, and over 1,000 cases in 1990. Thus, if the AIDS epidemic continues to spread as expected, Sacramento County can expect 3 new cases of AIDS reported daily in 1990.

Health Care Costs

These figures are sobering considering that the current number of AIDS cases are already proving to be a heavy burden on existing resources. The average cost of care for a person with AIDS in California (outside of San Francisco and Los Angeles) from the time of diagnosis until death (approximately 18 months) is $91,000. (1)

By 1990 health care costs for persons with AIDS will be over $10,000,000 a year. Sacramento County can expect to pay one-third of that sum ($3,500,000) for health care services to indigent AIDS persons.

(1) A quantitative Analysis of AIDS in California, George Deukmejian, Governor California, Kenneth Kizer, MD, MPH, Director, Department of Health Services, March 1986.
FINDINGS A

The Mayor's AIDS Task Force submits the following findings and recommendations for information and action for dealing with the AIDS public health problem.

TRANSMISSION & PREVENTION

Findings

HIV does not spread through casual contact with an infected person. HIV does spread through unprotected sexual intercourse with an infected person, and through sharing IV drug paraphernalia contaminated with the virus.

HIV does not appear to spread within a household in which an infected person is living.

The risk of spreading HIV through blood transfusions has been nearly eliminated by the blood banking facilities through careful screening of donors and testing of donated blood.

Studies have proven that proper use of condoms (protected intercourse) can reduce the risk of sexually transmitting HIV.

In cities where extensive prevention programs through educational campaigns have been implemented the spread of HIV amongst gay and bisexual men is slowing due to greater awareness and use of 'safe sex' practices. Sexually transmitted diseases in gay men in San Francisco has declined by over 90% in the past three years, reflecting this greater awareness.

HIV is transmitted only through blood or sexual contact. There is no risk to uninfected co-workers or the general public as long as they avoid contact with blood or sexual contact with the infected individual.

Methods of preventing AIDS may raise sensitive issues of civil rights, rights to privacy, public aversion to open discussion of matters pertaining to sexual practices, IV drug use, and financial cost of preventing spread.

The role of antibody testing in slowing and preventing spread of HIV is controversial, except in the cases of screening of blood for transfusion in organ transplant and artificial insemination programs where it has been very beneficial. Therefore, the use of HIV antibody testing as a tool to decrease the spread of AIDS is appropriate in particular circumstances. Proponents of widespread testing cite better targeting of educational materials and counseling toward infected individuals. Opponents of widespread testing fear increased discrimination and harassment of groups and individuals.

There is no evidence that quarantine would prevent spread of HIV. In addition, quarantine represents a tremendous encroachment on civil liberties.
Implementation of a quarantine program would be far more costly than other more effective prevention methods. Furthermore, voluntary antibody testing would virtually cease and opportunities for education of infected individuals would be lost due to fear of discovery by these individuals. However, when all strategies have failed quarantine might be appropriate in instances of deliberate or irresponsible behavior by infected individuals which results in exposure of citizens to infection.

Decriminalization of possession of IV drug paraphernalia should be considered as a means of decreasing spread of HIV amongst drug users. IV drug users cite criminal penalties for possession of IV drug paraphernalia as a major reason for sharing paraphernalia. Sharing such paraphernalia contributes to the spread of AIDS.

CDC guidelines stress the routine enforcement of precautions designed to prevent the transmission of bloodborne infectious diseases for workers whose job requires needles or other instruments penetrating the skin. This includes education on the epidemiology, modes of transmission, and prevention of HIV infection.

Recommendations

It is recommended that:

1) All City and County employee groups who are first responders or direct service providers be given mandatory in-service training on AIDS and effective infection control practices.

2) Education be provided about the anti-HIV antibody test for all individuals at risk; and that pre and post testing counselling sessions for those tested be provided; and the City and County of Sacramento assume responsibility for providing funding for testing, related education, and counselling programs.

3) The City and County develop a 'Five Year' plan for AIDS education and service provision which is annually reviewed.

4) Public officials in the City and County support and participate in a visible education campaign on AIDS prevention.

5) The City and County adopt the Centers for Disease Control guidelines regarding the prevention of AIDS in the workplace.

6) The City and County recommend to the State that in light of the AIDS crisis the State should decriminalize laws which define possession of IV drug paraphernalia as criminal.
EDUCATION

Findings

Until the development of an AIDS vaccine, education will be the only means for the prevention of the AIDS diseases. Education efforts should be directed to (a) people who engage in high risk activities (see glossary), (b) general public who do not engage in high risk activities.

The public will need to be prepared for the explicit nature of effective educational materials. Educational materials must be: a) explicit to members of each particular risk group describing the risks and the means to reduce or eliminate those risks; b) written in a language and a manner which will be well received by such a group; c) widely available as a resource to all members of such groups; and d) utilized when formulating and adopting risk reduction policies.

Education alone may have little impact on the spread of the AIDS virus amongst IV drug users however, it is still the primary prevention alternative available at this time.

Educational efforts with regards to AIDS should:

- Be extensive.
- Be supported by government as well as private sectors.
- Be aimed at correcting misconceptions.
- Emphasize that AIDS is a sexually transmitted disease.
- Emphasize that AIDS is transmitted through shared paraphernalia and IV drug use.
- Reach all sexually active populations (including adolescents).
- Emphasize personal responsibility for contracting as well as transmitting HIV.
- Include all media (television, radio, newspapers, billboards, public and professional lectures).
- Be a required part of health education and 'sex' education classes.
- Include mandatory education of incarcerated drug users.
- Be a mandatory in-service training program for all City and County EMS/EMT first responders. The Center for Disease Control (CDC) has published employer guidelines explaining necessary health precautions for employees.

Recommendations

It is recommended that:

1) The City encourage the implementation of community risk reduction and health education programs to effect behavior change regarding high risk sexual practices and use of IV drugs. This includes mandatory education of incarcerated individuals and facility staff with reference to sexual transmission and needle use.
2) AIDS education programs be required for all clients in outpatient and residential drug and alcohol treatment facilities.

3) The City encourage the County Superintendent of Schools to rapidly develop an appropriate AIDS curriculum for grades 4 to 12.

4) City and County school districts distribute the brochure "School Childern and AIDS" to the parents of all school age children.

5) The City and County recommend that the Chancellors of the Community Colleges, State Universities, and the University of California systems, incorporate AIDS education in teacher credentialing and continuing educational credit programs.

6) The City and County distribute material describing AIDS and the need for community education utilizing Utility Billing mailing mechanisms or other appropriate systems.

HUMAN SERVICES

Findings

Persons with AIDS require the most extensive and sophisticated medical services available as they develop recurrent life threatening illnesses.

The AIDS medical crisis has generated a mental health crisis involving persons with AIDS, their families, and friends. Therefore, there is a need to provide a comprehensive and coordinated medical and psychological services program.

There is a serious lack of medical care, residential or convalescent care, and mental health care of HIV infected individuals.

In the City and County of Sacramento specialized service needs for infected individuals have not been adequately met to date and the demand for services will increase substantially over the next few years.

Demands for services will increase sharply in the next few years.

The $35.00 per day of Medi-Cal reimbursement for skilled nursing care is inadequate to cover the costs of care for HIV infected individuals. The owner-operators of care facilities have raised liability and insurance questions regarding AIDS patients which are unresolved at the State level.

Residential treatment facilities may require incentives in order to admit HIV infected individuals.

Mental health services are inadequate or non-existent for HIV infected individuals. These services must be developed and expanded to accommodate all individuals in the high-risk groups who are not testing positive for HIV yet need mental health services.
The Clinic for AIDS and Related Disorders at the University of California, Davis Medical Center and the Sacramento AIDS Foundation need resource assistance in order to continue to effectively provide prevention and health care services plus an increase in those resources as the numbers of HIV infected individuals increases.

The resolution of owner-operator liability and insurance issues should be addressed and resolved at a state level so that private facilities will accept persons with HIV infection.

Recommendations

It is recommended that:

1) The City ask that the County establish an AIDS in-service training program for mental health practitioners and social workers. This includes establishing a program to prevent provider 'Burn-out' for those caring for persons with HIV infection.

2) The City and County provide financial and resource assistance to the Clinic for AIDS and Related Disorders, University of California, Davis Medical Center and the Sacramento AIDS Foundation.

3) The City ask the County to prioritize the establishment of mental health services to people with AIDS and related conditions as a priority.

4) The City and County assist in the planning and establishment of an independent residential care facility for persons with HIV infection as soon as possible.

5) AIDS education programs be incorporated in family planning clinics and other community clinics beginning at the initial visit of all women at risk for HIV infection.

6) Sacramento County provide for medical care of indigent persons with HIV infection at County facilities and the Clinic for AIDS and Related Disorders, UCDMC.

7) The County establish a specialty clinic for people with AIDS in its currently available clinic facilities for the care of the medically indigent adult (MIA) patients or contract for such services to private providers.

8) The City and County fund a coordinator to assist in planning and coordinating of all AIDS related services in Sacramento County.

9) The City and County advocate to the State Legislature a resolution of owner-operator liability insurance problems for nursing, convalescence, and board and care facilities so that private facilities will accept persons with AIDS.
DISCRIMINATION

Findings

People's natural, but very volatile, fears and anxieties about the unknown, death, and sexuality, have fueled an almost hysterical paranoia related to the AIDS epidemic.

Unfortunately, some legislators and members of the general public have suggested policies which will have negative consequences for stopping the spread of AIDS and providing health care. People with and at risk for contracting AIDS have experienced an extensive array of forms of discrimination. These vary but do include discrimination in employment, housing, insurance, education, prevention, research, and medical and social services.

Recommendations

It is recommended that:

1) The City and County adopt comprehensive anti-discrimination ordinances for people with HIV infection. These ordinances should include provision for civil remedies including actual and injunctive relief.

2) The City and County designate the City-County Human Rights and Fair Housing Commission to act as a clearinghouse for the documentation of AIDS related discrimination. In that capacity the Commission should investigate and attempt to conciliate and mediate instances of discrimination in housing, employment, public service, and accommodation.

3) The City and County advocate at the federal level recognition of people with ARC (AIDS Related Complex) which results in disability so they may receive the full range of health, financial and social benefits currently received by those classified as disabled.

The Task Force members strongly encourage the adoption of all the recommendations listed. These recommendations, if implemented, will effectively decrease rates of new infection in the City and County thus preserving human and financial resources.
Exhibit (1)

COMMITTEE MEMBERS
MAYOR'S AIDS TASK FORCE

1) Neil Flynn, M.D.
   Director
   Clinic for AIDS & Related Disorders
   Department of Internal Medicine
   U.C.D. Medical Center

2) Paul Horn, M.D.
   Sacramento County Disease Control

3) Kate Guzman
   Director
   AIDS Foundation

4) Ida Russell
   Member
   Sacramento School Board

5) Rick Martinez
   Secretary-Treasurer
   Police & Fire Union Representative

6) Sandy Pomerantz, M.D.
   Medical Director
   Sacramento AIDS Foundation
   Co-Director
   U.C.D. Clinic for AIDS & Related Disorders

7) Bruce Pomer
   Director, Governmental Affairs
   Health Officers Association of California

8) Leonor Fernando, M.D.
   Sacramento Blood Center

9) Vicki Bailey
   Counselor
   Aquarian Effort

10) Stan Hadden
    Senator Roberti's Office

11) Billie Sullivan, MEdP
    Program Coordinator
    UCD Northern Central California
    Hemophilia Program/Department of Pediatrics
    School of Medicine, UCD Medical Center
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome.</td>
</tr>
<tr>
<td>ARC</td>
<td>AIDS Related Complex.</td>
</tr>
<tr>
<td>CDC</td>
<td>Center for Disease Control.</td>
</tr>
<tr>
<td>High Risk Activities</td>
<td>Unprotected sexual intercourse &amp; sharing intravenous drug paraphernalia.</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus.</td>
</tr>
<tr>
<td>HTLV-III</td>
<td>Human T-cell lymphotrophic virus, strain 3.</td>
</tr>
<tr>
<td>IV DRUG USER</td>
<td>Persons who intravenously inject illicit drugs.</td>
</tr>
<tr>
<td>LAV</td>
<td>Lymphadenopathy Associated Virus.</td>
</tr>
<tr>
<td>MIA's</td>
<td>Medically Indigent Adults.</td>
</tr>
</tbody>
</table>
12) Michael Tscheu, LCSW  
   Director, Sutter/VNA Hospice Care  
   Sutter Community Hospitals

13) Kenneth Lee, M.D.  
   Internal Medicine  
   Kaiser Hospital

14) Ann Tinsley  
   Health Committee Member  
   Chamber of Commerce

15) Mary Kimball  
   PTA, 3rd District

JLA/jb (0342S)
III. Establishing Goals and Objectives for a 5 Year AIDS Plan for the State of California

A. The State Commission on AIDS

The call for a State Commission on AIDS is seen as an attempt to establish a coordinated overseeing body charged with the creation of new systems of services, prevention and education through developing existing programs. It is important to have representation of various governmental departments, AIDS service providers, academic institutions, religious organizations, public health experts, health planners and insurance and business interests on the Commission.

The Commission should establish an AIDS Institute, similar to that in New York, to address the personal, economic, political and social impact of this disease in California over the next five years. The AIDS Institute would be the primary staff for the Commission.

B. The Role of the AIDS Institute

The AIDS Institute should be responsible for a wide-variety of programs ranging from sponsorship of scientific investigation to the promotion of supportive services for affected persons. Staff would not be responsible for utilization review or quality assurance of AIDS treatment but would work closely with hospital standards and surveillance staff and the proposed review organization would ensure that as problems in the community are identified, the institute would assist providers in developing solutions as part of its overall activities. The Institute would have a specific responsibility to ensure a full continuum of both medical and non-medical services are available to persons with AIDS and to ensure the distinctive needs of the principal high risk communities are identified and met. This appears to fill an important cohesive role between the existing administrative structures of state, local governments, hospital administrators, AIDS service providers and people who are attempting to solve problems and fill gaps in service provision. The Institute staff could be important facilitators in this necessary process to establish AIDS planning.

C. Main Functions of the AIDS Institute

1. Staffing and advising the members of the State AIDS Commission on legislative and policy recommendations.

2. Ensuring the policies, goals and objectives of the Commission and are fulfilled.

3. Assisting state, regional and local administrators with AIDS related policies, systems and problem solving.

4. Developing and coordinating plans for giving ongoing technical assistance to regional AIDS Councils.
C. Main Functions of the AIDS Institute (cont.)

5. Assist hospital standards and surveillance staff with utilization review and quality assurance for AIDS treatment.

6. Ensure that a full continuum of medical and non medical services are available to persons with AIDS.

7. Ensure that ongoing research, data collection, information sharing, and program evaluation will be utilized fully in the statewide planning process.

8. Developing policy recommendations to the Commission to establish public/private incentives in developing efficient and cost effective health care for persons with AIDS.

D. The Appointment of a Review Organization/Californians

The Commission may also appoint a review organization to be concerned with monitoring the activities of the proposed AIDS Treatment Centers and to conduct a comparative analysis of the care of patients in non-designated hospitals. The expanded nature of the statewide AIDS program and the introduction of case management in the hospitals requires a great deal of collaboration, particularly during the initial period of implementation.

1. Some reasons why this is preferred for AIDS:

   a. The unique medical characteristics, high cost and devastating impact of this disease require the development of appropriate data collection, utilization and quality assurance protocols in collaboration with the designated centers.

   b. The case management model puts different responsibilities on the centers. These expanded responsibilities require hospitals to extend themselves much further into non-medical and community services than current discharge planning practise. This requires new skills and sensitivity of a review organization, both to the behavior of participating hospitals and to the opportunities and limitations of the service systems on which the hospitals must rely.

   c. It is possible at this stage of the epidemic to tentatively develop alternative cost effective treatment programs such as home health, skilled nursing facilities, and outpatient care. The data to evaluate the proposed model standards is still to be collected. It is important as we establish the provisional AIDS health care continuum, to build measurable goals into the systems, and standardize data collection at all levels.
2. The review organization will be responsible in meeting the following objectives.

   a. Evaluation of case management models
   b. Utilization review program
   c. Develop and conduct a comparative analysis of care programs for patients with AIDS.
   d. Design protocols and procedures for assuring quality of care surveillance in a systematic fashion for all risk groups.
   e. Monitor the level, type and amount of services
   f. Assess and evaluate the effectiveness of centers' discharge planning, viability and effectiveness of referral patterns for various levels of care and types of services.
   g. Monitor the availability and accessibility of community and institutional services.
   h. Conduct overall evaluations on an ongoing basis of the population served and the experience of centers in serving them.
   i. Establish standards for data collection including cost of care, type of care, and effectiveness of care.
   j. Review and evaluate the health care continuum as it impacts patients in different stages of the disease (see Orange County's 8 stages of disability model)

E. The implementation of the program goals outlined in section 1 and 2 by establishing regional AIDS Treatment Centers.

1. Necessary legislative approval of the structure and funding required to instigate the goals and establish the State Commission on AIDS and the AIDS Institute.

2. The Office of AIDS develops a regional inter-county structure which allows for the existing AIDS networks and service delivery systems. Representatives from those counties, health officers, AIDS service providers, business, insurance, philanthropic, religious, health planning, academic and other significant related communities will be appointed by their counties to serve as members of Regional AIDS Council which will be advisory to the AIDS Commission, the Office of AIDS, and Local Boards of Supervisors. Technical assistance should be provided to these councils by the Aids Institute. Regional AIDS Councils will be concerned with local long range planning, resource development and problem solving at local levels.
3. The office of AIDS develops a system for allocating grant funding to the regions with strong recommendation from the Regional AIDS Councils as to appropriate systems of funding and contact allocation. It may be appropriate for the State to request one comprehensive agreed plan in a particular region to improve collaboration at local levels, similar to the process establish in the California metropolitan areas involved in the Robert Wood Johnson AIDS Health Program applications. (Areas who sent more than one application were requested to work together on improving proposals and collaborating with competing applicants. The 4 areas who submitted proposals in California and so as unified countywide consortiums).

The most important issues which emerged during the 5 site visits were:

The need to increase the Medi-Cal reimbursement rate for AIDS related care, particularly in the areas of skilled nursing home, hospital care and community based alternative programs which meet client needs cost effectively. The Placerville Convalescent Home was being reimbursed $46 per day for a patient who was costing them $70 per day. Many nursing facilities are unwilling to be involved in the provision of AIDS services unless Medi-Cal increases their rates. The extra expenses would be needed to cover staff education, infection control, labor, mental health, case management services and increase liability and other insurance.

A 1986 survey of 148 skilled nursing facilities in Los Angeles showed only 2 nursing facilities had accepted people with AIDS. The lack of alternatives is causing problems for discharge planners and insurance case managers. In Los Angeles, the Visiting Nurses Association has been providing subsidized home health care through contributions from United Way. In 1986, 25 patients receiving home health care in Los Angeles would have to be admitted to County General Hospital when funds for the program ran out. They were finally assisted by funding from the county and state to continue with their home health care.

A. The need for regulatory reform in licensing residential and health care facilities

In San Francisco, one of the most enterprising and innovative community sponsored projects to take care for people with AIDS is the 'Coming Home' hospice project in the Castro district. The local Catholic Parish and a group of dedicated hospital staff and volunteers under the auspices of the Pacific Presbyterian Medical Center, applied to the Department of Health Services for licensing. Their goal was to provide 24 hour nursing care in a hospital setting for 15 terminally ill AIDS patients. The project was a remarkable community success with public funding for the project was marked dollar for dollar by the enthusiasm and altruism of the local community. Two years later, the facility has just been opened, and attracted major media attention recently when the British Minister of Health and Social Services and the U.S. Surgeon General visited the facility.

However, 'Coming Home' represents a classic case when community resources, skill, and need are being hindered by bureaucracy and policy. Soon after applying to the Department of Health Services for licensing, 'Coming Home' was referred to the State Department of Social Services to be licensed under Title 22 as a board and care facility. To
A. The need for regulatory reform in licensing residential and health care facilities (cont.)

meet all the regulations each room was to be secure with its own lock, and each resident was to be regarded as a tenant of the facility. Nursing and attendant care could not be provided by the board and care facility, but Visiting Nurses could be contracted to care for individual patients in the facility.

The State Department of Social Service has never dealt with a facility like this and initially was unwilling to license a facility which would, for all intents and purposes, be providing health care. The issue was when does a licensed residential care facility become a health care facility? 'Coming Home' fell through the cracks.

The patience and fortitude of the pioneering staff from the 'Coming Home' team is to be commended. Recently a site visit from the two State departments with testimony from local and national hospice leadership has helped to develop some common ground. The visitors were impressed by this new model of residential hospice care. A joint committee composed of representatives of the Department of Social Services, Health Hospice organizations, and the Shanti Foundation could help to develop the new policies on all levels of residential care where intermittent nursing care is needed.

In reforming Title 22 Division 6 Chapter 6, adult residential facilities will need to include some provision for health related services, specifically intermittent health services from an outside agency. Intermittent care could be provided by a residential facility which could become a new licensed category called Residential Hospice Facilities. Another issue which would need to be examined simultaneously is the assurance that additional reimbursement for intermediate care facilities for the developmentally disabled (which is under the Department of Health Services) is not lost to residential hospice facilities if they come under the policies of the Department of Social Services.

Residential hospices as a separate category is already allowed under Federal law and there is potential for reimbursing hospice care through Medi-Cal. The proposed committee should also be charged with assisting community agencies in metropolitan areas who would like to establish Shanti-based housing models. One social service administrator who wanted to assist a 'grass roots' Southern California residential project felt he could not involve his organization in a program which potentially could cause liability insurance and zoning problems.

Independent living will become another highly cost effective and patient preferred service component in the AIDS-care continuum and it is important to clarify the legal insurance
A. The need for regulatory reform in licensing residential and health care facilities (cont.)

and regulatory issues which are hindering the professionalization and development of these services on a larger scale. Technical assistance could be provided to community based organizations who would like to develop Shanti-type housing programs and 'Coming Home' residential hospice facilities. Every site visit highlighted the need for this service (the 'Coming Home' Program description which is enclosed, it is useful in explaining the issues just discussed).

B. The need to reform existing health related programs to include and be utilized by people with AIDS.

Several important existing programs could easily include people with AIDS and their immediate families and support systems.

1. Family Survival Project

AB 2913 enacted as Chapter 1658 (1984 statutes) requires the State Department of Mental Health to contract with an agency to serve all diagnostic categories of brain impairments through coordinating information, provide technical assistance and services, establishing regional resource centers and providing direct family services. They would provide:

a. Counselling and problem solving consultation for families caring for brain damaged adults.

b. Monthly support groups.

c. Legal and financial consultation or power of attorney, estate and financial planning.

d. In-home support personnel, day care and transportation for up to 40 hours per month to families caring at home for a brain damaged adult.

e. Counselling and referrals to licensed professionals for individual family therapy and information about diagnostic problems, behavior management and patient care.

f. Special training and workshops on topics such as diagnosis treatment, long term planning and stress management.

The legislation would need to redefine "families" to include the primary social and emotional support system of the patient as many of the target population are unmarried men living apart from their families. AIDS and HIV
1. The Family Survival Project (cont.)

infection should be listed with the list of brain damage factors. Further funding and resources should be allocated to the Department of Mental Health to provide AIDS related services in all of the above categories.

2. The Genetically Handicapped Persons Program

Under SB 1483 (Holden 1976) and SB 929 (Sieroty 1979) GHPP is a program of the Department of Health Services which coordinates the care and helps pay for medical costs of persons with:

Hemophilia and other genetic coagulation defects
Cystic Fibrosis
Sickle Cell Disease and Thalassemia
Selected hereditary metabolic disorders including PKU

The program promotes high quality coordinated care through case management services and collaborates between local care providers and the Comprehensive Center Team.

a. GHPP pays for medical care in the case of loss of insurance or Medi-Cal due to change in employment or income.

b. GHPP pays for service that are not covered by other plans.

c. GHPP protects families who are self supporting from undue financial hardship at times of unusually high medical expenses and makes it possible for the self employed and part time employed to receive essential medical care without insurance coverage.

Benefits include:

a. Outpatient and inpatient hospital care including X-ray and laboratory services.

b. Dental and medical services including home health care medications, vitamins, food supplements, blood products, oxygen, physical and occupational therapy, speech therapy, psycho-social services, respite care, prosthetic and orthopedic appliances, medical equipment, medical transportation and maintenance for clients in financial need.

Providers must accept the state rate for services as full reimbursement through long term institutional care is not covered when patients can no longer be maintained at home.

Persons with adjusted gross family incomes exceeding $40,000 per year may and purchase services under the program at cost. Program expenses may be reduces through the use of health insurance, Medi-Care, Medi-Cal or other coverage before GHPP funds are used.
2. The Genetically Handicapped Persons Program (cont.)

The advantages of applying these two health bills to people with HIV infection stages 3 and 4 would create a stable and comprehensive public/private care package for people with AIDS and their primary care givers. All the important policy issues for AIDS are addressed in these two bills, including reimbursement for a variety of community based care, insurance coverage, standardizing case management, respite care, mental health services, agreement on fixed costs for providers, and eligibility for services.

3. Other Issues

a. As care in the home becomes more important, homemaker services should be given more vigorously to people with AIDS/ARC. The policy relating to the employment of family members of the patients primary emotional and social support system. Many rural areas rely on volunteers providing this vital service for patients who can maintain themselves at home with minimal support. Family members, spouses, lovers and friends who provide this service should have the opportunity to be reimbursed where a patient is normally eligible for this service.

b. Patients with individual or small group health insurance plans do not have COBRA guarantees for continuation policies. Medi-Cal should look into extending the protections to these patients.

c. Data should be collected on the health insurance and Medi-Cal eligibility situation and treatment experience of stratified groups of California AIDS patients to better understand how costs are being shared by various payers (i.e., insurers, HMOs, individuals, county hospitals, VA, Medicaid, Medicare, etc.)

d. Study the possibility that certain hospitals, HMOs and health insurance companies will be caring for such a disproportionate share of AIDS patients that their financial future is in jeopardy. What can be done?

e. Do certain communities, e.g. San Francisco, face an impending shortage of hospital beds for AIDS patients? If so, what can be done?

f. Prevention and treatment programs are extremely necessary in the states juvenile and adult detention facilities. Certain counties are discharging patients from jails who have AIDS (many of whom are minorities with no support system or resources). There is need to address the issue of prevention and treatment immediately and to create policies which forbid the release of prisoners without adequate care and support.
3. Other Issues (cont.)

g. Solutions to the problems arising from the financing of care for HIV infection should be achieved within a mechanism which ameliorates existing catastrophic health care problems. Measures could include a state based insurance risk pool for the uninsured and those with catastrophic illness. Eligibility criteria would include people with HIV infection similar to the GHPP eligibility and scope of care.

h. The majority of patients are faced with income maintenance problems and there is no substantial research which shows how people are surviving, paying for medical expenses or how the social security and welfare system is supporting them. Many community agencies in the 5 counties surveyed are providing housing, food and medical subsidies which are very basic and in many cases are only factors keeping AIDS patients from homelessness, hunger, and destitution. Aid for AIDS in Los Angeles and the Orange County AIDS Foundation give grants to clients who want to continue living in their existing apartments. The existing level of need (30-35 new intakes each month) will not permit these subsidies to continue at existing levels for much longer. Alternative programs will have to be developed following more thorough research into income maintenance of people with HIV infection stages 3 and 4.

Recommendations on Policy Issues

1. The goals of the Comprehensive Treatment Program are agreed upon by an appointed State AIDS Commission with an appointment budget approved to meet the goals.

2. The AIDS Institute will be created to advise the commission on policy recommendations which are outlined briefly in this section.

3. The Commission appoints a committee to make recommendations on the Medi-Cal reimbursement issues affecting AIDS service delivery, particularly in the areas of skilled nursing facilities, home health care and residential hospice care.

4. A joint committee of the Department of Social Services and Department of Health Services makes recommendations to the Commission on the issues affecting residential hospice, adult residential facilities, and other subacute care facilities for people with HIV infection stages III and IV, so as to expedite appropriate cost effective care facilities.

5. Technical assistance should be provided by the AIDS Institute, to communities developing home health, adult residential facilities, residential hospices and independent residences for people with HIV infection 3 and 4.
Recommendations on Policy Issues (cont.)

6. Technical assistance should be provided by the AIDS Institute to those counties developing Regional AIDS Councils for long term planning and development of local AIDS services.

7. The AIDS Institute should advise the Commission on reform and augmentation of existing legislation and policies to improve access to services for people with HIV infection and issues outlined in the Family Survival Project and Genetically Handicapped Persons Program and other appropriate health and social services programs.

8. The Commission should appoint a committee to develop recommendations on various health reimbursement issues for catastrophic illness. This should include the insurance community, existing providers and counties heavily impacted by the AIDS epidemic.

9. The commission should appoint a committee to develop policy recommendations for AIDS treatment, prevention, and education programs in juvenile facilities and prisons and the care of persons with HIV infection.

10. The Commission should appoint a committee to develop recommendations on prevention, education and treatment programs for ethnic minorities in the state and an equitable way to ensure resources and technical assistance are made available to them.

11. The commission shall require the development of research and data on the following issues:

Income maintenance for persons with AIDS/ARC

Comparative cost of care for patients treated in AIDS treatment centers and elsewhere.

Evaluation of services, quality assurance and utilization review of the AIDS health care continuum.

The effectiveness of existing administrative, advisory, and informational systems which support the AIDS service continuum throughout the State and recommendations to improve these systems.
Pacific Presbyterian Medical Center
Coming Home Hospice
Facility Program Description

Coming Home Hospice will be a residential hospice facility for fifteen people with terminal illnesses. It will be operated by Hospice of San Francisco, a program of Pacific Presbyterian Medical Center, which is a comprehensive health care organization offering among other things, services to keep San Francisco's elderly, ill, disabled and dying at home and in their communities. This facility will fill the significant gap between care in the home and care in health care institutions such as hospitals and nursing homes. It is intended for people who are dying, who do not need or want institutional care, but who do need supervision and help with activities of daily living.

The goal of Coming Home Hospice is to offer a warm, home-like environment for people with AIDS and other terminal illnesses whose homes are either no longer available or are inappropriate for the provision of care.

The purpose of Coming Home Hospice is to provide residential care for people with AIDS and other terminal illnesses who do not require the level of care provided in an acute care setting such as a hospital, or in a skilled nursing facility. A residential care facility is necessary because some people with AIDS who need care lose their homes for reasons related to their illness and the public hysteria over AIDS. Other people with AIDS who need care live alone and/or lack the personal support networks that can help provide for their care in the home. Also, older people with other terminal illnesses who live alone, or with a frail elderly spouse unable to provide adequate care, may need assistance with residential care needs.

The program within Coming Home Hospice will provide living accommodations for people who need 24-hour supervision and care to provide for personal safety and to help with the basic activities of living: cooking, cleaning, bathing and laundry. The facility will not have an institutional atmosphere. Instead, it will be as inviting and comfortable as possible. The facility will have fourteen bedrooms on two floors, with one bedroom accommodating two people. There will be a living room on each floor, handicapped accessible bathrooms, a dining room, pantry and kitchen, laundry facilities, a commercial elevator, and an exterior ramp providing handicapped accessibility. A second stage of renovation will provide a handicapped deck which will be accessible from the dining room, offering a secluded outdoor landscaped space for use by residents and their loved ones. Residents will be terminally ill people in need of
residential care whose homes are no longer available, or who can no longer be maintained in their own home. The average length of stay for such residents will be 45 days, which will be the final days of life before death.

For hospice clients requiring the level of care available in a skilled nursing facility, Hospice of San Francisco has established a relationship with Garden Sullivan Hospital. While this provides specialized care for pain control and symptom management, as well as respite for family members, Garden Sullivan does not meet the growing need for residential care in a group setting.

Coming Home Hospice will be administered by Hospice of San Francisco's Director of Hospice and AIDS Programs. The actual facility services will be the responsibility of a Residence Manager who will be on-site, and available 24 hours a day.

Residential Care and Supervision
Residential care and supervision in Coming Home Hospice will include the following:

a. 24-hour attendant care coverage which will provide assistance with dressing, personal grooming, bathing, other personal hygiene, and laundry;

b. Supervision of client's daily activities and schedules, as well as the maintenance of house rules for the client's protection;

c. Maintenance and/or supervision of client's cash resources or property;

d. A food service program which will provide an on-site cook seven days a week, menu planning, food purchasing, nutritional consultation, food preparation and food storage, all geared to monitor food intake and special diets;

e. A janitorial and building maintenance program which will provide daily cleaning of bedrooms, bathrooms, kitchen, diningroom, livingrooms and common areas in order to insure a sanitary and orderly residential environment;

f. Assistance for clients in taking self-administered medications as needed; and

g. Centralized storing of medications in a safe, locked place, including a locked refrigerator for medications requiring refrigeration, not accessible to persons other than employees responsible for the supervision of the centrally stored medication.
Hospice Care
Home care and hospice services will be provided to residents in this group residential setting by Hospice of San Francisco's professional staff in the same manner they now provide such care in over 63 client's homes on a daily, intermittent basis throughout the City and County of San Francisco, as well as northern San Mateo County.

Hospice care is a program, as well as a philosophy of care, for people confronting terminal illness who choose to remain at home, or in a home-like environment, in dignity, with the care and support of their loved ones. Hospice of San Francisco provides intermittent skilled care and humane support for such people with terminal illness, and for their families and friends. Hospice care offers an individualized program of medical, social, psychological, spiritual and practical support for dying people, as well as bereavement counseling. Hospice care is palliative care, emphasizing pain control and symptom management, rather than curative medical care when this kind of care is no longer a realistic option. A multi-disciplinary team approach is used in the provision of hospice care, which utilizes a nurse and social worker to provide the professional level of intermittent health care, attendants to provide the para-professional level of residential care and supervision, and trained volunteers to provide practical support.

Hospice services within all home or home-like settings include the following:

a. Intermittent medical and nursing care; pain control and symptom management.

b. Social work services.

c. Attendant care provided by home health aides and home makers.

d. 24-hour, 7-day a week nursing on-call availability.

e. Medicare-certified hospice program.

f. Practical support provided by trained volunteers.

g. Emotional and spiritual counseling, family support group and bereavement support program.

h. In-patient services at Garden Sullivan Hospital for patients in need of acute care or skilled nursing facility care.
Hospice nurses and social workers providing the professional level of care will not be on staff at Coming Home Hospice. Just as in any other private home setting, they will visit their clients in this home-like environment on an intermittent basis, provide their services, and depart.

**Transportation Arrangements**
Transportation will not be provided by Coming Home Hospice. Transportation must be arranged by the resident or designated other and purchased from an outside organization.

**Program Consultation**
Program Consultation will be provided as needed by staff of the AIDS Activity Office, Department of Public Health for the City and County of San Francisco, or by other parties appropriate for the monitoring of operations of a licensed residential care facility. Medical consultation or other health care consultation will be made available through the services of the Hospice of San Francisco or VNA of San Francisco. Other consultants have not been identified at this time.

**Social, Educational and Recreational Activities**
Social, educational and recreational activities will be directed by the Residence Manager, with participation and support from the hospice volunteer program. The two living rooms and the dining room will be focal points of social and recreational activity inside the facility. A landscaped deck off the dining room will be the focal point of outside social and recreational activity. A library is planned for the ground floor lounge which will contain books, musical tapes, meditation tapes and video tapes. Each resident bedroom will have a television set, with VCR capacity. A piano is located in the upstairs living room, for the use of residents and visitors alike.
Coming Home Hospice
Rules of Discipline

1. No smoking will be allowed in any public areas. Smoking in bedrooms by residents and visitors may be permitted by the Residence Manager.

2. Family members, lovers, spouses, children and friends may not live with residents at Coming Home Hospice.

3. Family and friends will be admitted to visit residents as required by resident's wishes and/or status.

4. Alcohol use will be permitted at the discretion of the Residence Manager, only if such use does not cause disruption to other residents, visitors or staff.

5. All performance groups shall be approved by the Residence Manager. The number of people in a performance group will be limited, from 7 to 10 people. Time limits for such performances shall not exceed 30 minutes.

6. Members of organizations providing assistance to persons living at Coming Home Hospice will be allowed limited access to visit resident as required to complete work. Such visits will be authorized and monitored by the Residence Manager.

7. Members of organizations not providing assistance to persons living at Coming Home Hospice will not be allowed access. If such members are friends or relatives of the resident, access will be controlled as described above.

8. No members of the communications media will be allowed access to Coming Home Hospice unless approved by the Director of Hospice of San Francisco, or other person in the Director's absence.

9. The Residence Manager may arrange a 15 minute tour on the first Monday of every other month beginning in May 1987 for visitors from other cities/countries. No tours will be granted at other times unless specifically authorized by the Director of Hospice of San Francisco, or designee.
Coming Home Hospice is a program of the Visiting Nurse Association (VNA)/Hospice of San Francisco.

1. Admission Criteria
Only persons eligible for admission into these programs and who meet the following admission criteria will be considered for residency. Persons followed by other home health agency or hospice programs will not be eligible for admission unless complete transfer to the VNA/Hospice of San Francisco occurs.

2. Terminal Illness
The adult or child must be in the terminal phase of his/her illness and have a prognosis of six months or less to live. The prognosis must be confirmed in writing by the primary physician. The person may have a diagnosis of AIDS, ARC, or other terminal disease.

3. Neurological Impairment
The person may be neurologically impaired due to opportunistic infections such as toxoplasmosis, and mycobacterium axium intra cellalare, or neurological complications related to other terminal diseases.

4. Residency Status
The person must be a resident of the City and County of San Francisco or Northern San Mateo County only.

5. Homeless Status
The person no longer has a home available, or the home is no longer appropriate due to needs for 24-hour attendant care and supervision.

6. Financial Status
The person's financial status will be reviewed by the Hospice social worker, using the Financial Assessment Tool. Payment for residential care services will be expected from the individual's financial resources or from Supplemental Security Income (SSI) payments. Payment for hospice care services will be expected from such payer services as Medi-Cal, Medicare, the City and County of San Francisco, private insurance and private pay. If a person is unable to pay for residential care services, or for hospice care services, the person may still be eligible for admission.
7. **Intermittent Care**
The person will have requirements for intermittent medical care which can be provided by a hospice nurse. The person will not have requirements for one-on-one 24-hour registered nursing or licensed vocational nursing coverage, or 24-hour intravenous therapy.

8. **Respite Care**
The person may have requirements for admission to relieve care demands on primary care providers at home for limited periods of time, or up to a five day maximum. This person must meet all other admission criteria. This person is not eligible for respite care if a primary care giver is not identified in the plan of care.

9. **Patient Ratio**
Of the fifteen patients admitted to Coming Home Hospice, two thirds (10) will generally be persons with AIDS or ARC, and one third (5) will be persons with other terminal diagnosis. This ratio may vary depending upon the demand for services at any time.

10. **Durable Power of Attorney**
Prior to admission, a durable power of attorney must be identified to make critical medical decisions and to handle pertinent financial matters after admission. Durable power of attorney may not be provided by a member of the staff or a volunteer of Hospice of San Francisco.

11. **Admission Agreement**
The person, or designated other, must sign the Admission Agreement to Coming Home Hospice.
Admission Procedure

1. Individual making referral must provide the following information prior to making a referral and before the referral will be considered for admission:

   a. Written confirmation by the patient's primary physician of terminal prognosis of six months or less with AIDS, ARC or other terminal illness.

   b. Written confirmation of durable power of attorney.

   c. Written completion of Financial Assessment Tool.

   d. Completion of application forms for Medi-Cal, SSI, SDI, or other appropriate reimbursement source, or verification of current eligibility.

   e. Identification of primary care-giver, when appropriate, for respite.

2. Patient must meet all admission criteria.

3. Referral will be made to the Intake Nurse at the VNA/Hospice of San Francisco (861-8705).

4. Individual making the referral without appropriate forms will be mailed forms by the VNA/Hospice Intake Nurse as necessary to complete referral.
Discharge Criteria

1. The person dies.

2. The person no longer needs 24-hour attendant care and supervision.

3. The person requires acute hospital care for medical evaluation and treatment, and/or 24-hour skilled care.

4. The person demonstrates inappropriate or disruptive behavior.

5. The person uses illegal drugs.

6. The person has/uses a potentially harmful weapon.

7. Coming Home Hospice will not accept or retain the following:
   a. Persons with active communicable tuberculosis.
   b. Persons who require inpatient care in a health facility.
   c. Persons who have needs which are in conflict with other clients or the program of services offered.
   d. Persons who require more care and supervision than is provided in the facility.
   e. Any person whose primary need is acute psychiatric care due to a mental disorder.
### COMING HOME HOSPICE
### DETAIL, OPERATING EXPENSES
### (Projected) January 1-December 31, 1987

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<tr>
<th>Description</th>
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<tr>
<td>* Salaries</td>
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<tr>
<td>Residence Manager @ $23,400 FT ($1,950/month)</td>
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<td>$39,000</td>
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<td>Cook @ $15,600 FT ($1,300/month)</td>
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<tr>
<td>Fringe (Insurance, FICA, UI, etc.) at 22%</td>
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<td>* Rent</td>
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<td>* Utilities (Water, PG&amp;E, Garbage) (Estimate)</td>
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<td>* Food $4/day/resident for 15 residents x 30 days/month</td>
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<td>21,600</td>
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<td>(Food for family members will be paid for individually)</td>
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<tr>
<td>* Maintenance Coordinator ($12 per hour contractor) Approximately 15 hours/week</td>
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<td>9,600</td>
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<td>* Maintenance Supplies (Cleaning Supplies, Equipment Rental, Garbage, Lighting Replacement, Rug Cleaning, etc.)</td>
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<tr>
<td>* Insurance Rider To cover building General liability (Does not include any professional malpractice)</td>
<td>400</td>
<td>4,800</td>
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<tr>
<td>* Telephone (Does not include equipment costs or installation/donated)</td>
<td>500</td>
<td>6,000</td>
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<td>* Program Operational/Supplies (includes office supplies, photocopying, postage, printed materials, typewriter, etc. &amp; limited disposable supplies for residents-personal care articles, etc.)</td>
<td>650</td>
<td>7,800</td>
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<td>* Laundry (contracted) Based upon per item cost for sheets, draw sheets for resident linens. Includes laundry service and rental of linens.</td>
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### Miscellaneous (Contingency reserve)

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**Subtotal**: $12,815 $153,780

### 8% overhead to VNA

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**Totals**: $13,840 $166,080

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DF:ds  
10/30/86
SECTION II

PREVENTION

prepared by

Michael Gorman, Ph.D., M.P.H.
MEMORANDUM

To: Executive Evaluation Committee, Co-Chairs and Observers

From: Micheal Gorman, Ph.D., M.P.H., Project Consultant for Prevention

Date: April 2, 1987

Re: Prevention Planning Document

Attached please find the preliminary working draft of the Health Policy and Research Foundation of California's goals and objectives to guide AIDS prevention efforts in California. These recommendations address two program areas: (I) Public Health/Preventive Epidemiology; and (II) Educational and Behavioral Interventions. We are most interested in your comments and suggestions as to how these objectives might be improved upon, broadened or framed in a more appropriate fashion.

We are particularly interested in your reaction to the scope of the objectives. Please feel free to add others that you deem necessary.

Thank you for your consideration and we look forward to receiving your comments.
Introduction

The California Department of Health Services using CDC statistics projects nearly 50,000 cases of AIDS in California by 1991, with 37,000 deaths. By the end of 1991, nearly 1/3 of these cases are expected to come from outside the San Francisco and Los Angeles metropolitan areas. The purpose of this document is to give an overview for planning purposes of specific needs and targeted objectives caused by the AIDS epidemic.

Two areas of prevention concern are addressed: traditional public health activities (such as case reporting, serologic monitoring and evaluation of these efforts) and educational and behavioral modification efforts. The National Academy of Sciences and the 1986 Institute of Medicine's report Confronting AIDS was a catalyst for this process and its recommendations provided goals for the various objectives. Data for this report was obtained through research of the scientific and public health literature, consultation with the State's public health experts including State health officials, county health officers, scientists and community leaders. Site visitations were undertaken in 3 counties, selected to be representative of California's regions in terms of population, geography, AIDS incidence and public health infrastructure.

In addition, relevant data was compiled from Los Angeles and San Francisco counties, each of which have undertaken their own planning processes.

The results of this information gathering are the following goals and objectives which lay out the outline of a plan for AIDS prevention in California.

Goals and Objectives for the Prevention of AIDS in California

1. Public Health and Prevention Epidemiology

The following Institute of Medicine recommendations are particularly relevant to public health prevention efforts:

- The committee supports a vigorous program of early reporting of both AIDS and ARC cases (as soon as acceptable definitions for reporting ARC can be formulated) to local and State public health agencies under strict policies of identifiability.
- AIDS education should be pursued with a sense of urgency and a level of funding that is appropriate for a life-or-death situation. Greatly expanded educational programs to effect behavioral change are necessary for high risk groups and the public at large. These efforts
Goals and Objectives for the Prevention of AIDS in California
(cont.)

should be supported not only by the government, but also by experts in advertising and the media.

-> The decision of whether to be tested for antibody to HIV should remain a matter of individual direction, given the array of potential risk and benefits that the test poses for those tested. Testing should be encourage in light of its potential public health benefits. Mandatory screening of at-risk individuals is not an ethically acceptable means in attempting to reduce the transmission of infection. In addition, such a mandatory program would not be feasible in an open society.

-> Testing programs should be coupled with strong guarantees of confidentiality. Such assurances should perhaps be backed by punitive sanctions for unauthorized disclosure of antibody test results. The committee does not recommend compulsory reporting of seropositive test results.

-> Many state health authorities are of the opinion that there are already effective laws and regulations that could be made applicable to AIDS and when necessary, but public health statutes concerning infectious diseases are out moded and may not afford civil rights protections adopted by American courts. States should review their statutes to ensure compatibility with current concepts of confidentiality.

-> The committee does not favor the establishment or the use of compulsory measures for isolation or quarantine of AIDS patients or seropositive persons from the general population. There may be a need however, to use compulsory measures, with full due process protection, in the occasional case of a recalcitrant individual who refuses repeatedly desist from dangerous conduct in the spread of the infection.

-> As a general policy, children with AIDS should be admitted to regular primary or secondary classes. The CDC guidelines are recommended for further reference in this area.

-> The committee believes that a total national expenditure based on a per capita prevention expenditure roughly similar to that made in San Francisco is a necessary goal.

-> The committee urges that blood and plasma collection centers also establish administrative systems to further encourage self-deferral of donations and diversion of suspect blood to research while maintaining donor privacy.

For the purpose of this discussion, public health prevention efforts have been subdivided into: (I) Preventative Epidemiology (including case reporting); (II) Serologic Monitoring; (III) Evaluation; (IV) Test-linked Counseling; and (V) Administrative Support.
I. Preventative Epidemiology

Preventative epidemiology has traditionally been referred to as "surveillance" or case monitoring which is essentially the gathering of relevant demographic and quantitative data on individuals infected with the virus. Such information can be used to document progression of the epidemic, indicate infection rates for various sub-populations and provide important baseline information for health services planning and for targeting interventions. Salient monitoring activities have included review of medical records and vital statistics, regular communication with infection control personnel in hospitals and clinics, visits to physicians, partner contact tracing, as relevant, special investigations of AIDS cases that are unusual, such as those that appear to have no identifiable risk. Other important surveillance tasks include compilation of data for purposes of statistical reports. Most monitoring activities in California counties would be best described as passive, i.e. essentially relying on these mechanisms. As the epidemic moves beyond the traditional risk populations, it will be important to undertake a more active role in ascertaining the extent of the spread of HIV infection. To this end, particular outreach might be undertaken with physicians groups and more vigorous review of medical and discharge data be undertaken. In addition to these measures, confidential screening should begin to be undertaken as well as sentinel seropositive studies (see screening below). In short, program objectives under the heading of preventative epidemiology might be identified as follows:

(1) Each county should develop a need assessment and master plan for implementation of preventive epidemiology needs and hiring of personnel, i.e. epidemiologists, nurses, public health behavioral scientists, etc.
(2) Continue existing AIDS surveillance activities.
(3) Expand surveillance to be undertaken through implementation of active surveillance techniques, i.e. use of sentinel physicians, medical and discharge review.
(4) Set goals for numerous case reporting such as all cases to be reported within 30 days of diagnosis.
(5) Closely monitor disease rates in other sexually transmitted diseases such as gonorrhea, syphilis, hepatitis B in the respective populations of interest.

In addition to case reporting and disease monitoring, serologic monitoring of selected populations blindly, i.e. on an anonymous basis would prove useful in ascertaining extent of HIV infection rates.

(6) Perform blind serologic testing 2 times a year on samples of:

a. STD clinic patients
b. family planning patients
c. prenatal clinic patients
d. individuals seeking premarital screening
e. methadone clinic populations
f. others
I. Preventative Epidemiology (cont.)

(7) Periodic evaluations or "look-backs" over HIV data collection efforts and results can also provide useful information by which to guide future program efforts. To this end there should be:

a. Monthly tabulation of all data sources
b. Monthly reviews of programs in progress including such information as:

- delays at Alternative Test Sites
- delays of AIDS case reporting (and barriers to such reporting)
- education programs
- numbers of confidential tests
- press reports
- monthly AIDS data summaries including total numbers of cases, seropositivity trends, behavioral change indicators.

In addition to these programs, a primary vehicle of AIDS prevention will continue to be test-linked counseling.

As of March 1987, 32 California counties had 54 alternative test sites which had screened 15,706 individuals since March 1985. It is expected that in the forthcoming year demand at the alternative test sites will increase dramatically (several small counties have reported increases of 150% - 175% since December 1986) and the capabilities of the sites to handle more people will have to be expanded.

In addition to alternative test sites, confidential testing for HIV would be of great utility. For women attending prenatal clinics, individuals in methadone treatment centers, for individuals who have received transfusions prior to March 1985 and after 1977 as well as for individuals attending STD clinics and those members of high risk populations and low risk populations who might wish to be followed - confidential testing provides an important public health mechanism for the prevention of AIDS.

Objectives for test-linked counseling are as follows:

(8) Anyone in California seeking to be tested for HIV should be able to do so.
(9) All those seeking to be tested anonymously, should be able to be tested within 10 days of their request.
(10) All counties will offer anonymous testing programs for HIV on at least a sliding scale fee if not for free.
(11) All counties will provide opportunities for confidential testing on at least a sliding scale fee basis if not for free in:

- STD clinics
- family planning clinics
- physicians offices
- methadone treatment centers
I. Preventative Epidemiology (cont.)

(12) Mandatory testing of individuals should not be allowed as a prerequisite for entrance into drug treatment, or for incarceration or any other purpose.

Administrative support and coordination are key functions in addressing the needs of the epidemic. Inadequate support can result in chaos and at the very least in poor utilization of scarce resources and personnel.

(13) All counties with more than 10 cases of AIDS should establish an AIDS program offices and have a program coordinator with an appropriate background. Clerical support should be expanded as necessary, such clerical support not a luxury.

(14) All counties should develop AIDS policies, with regard to schools and the education of children with AIDS. As a general policy, children with AIDS should be admitted to primary or secondary classes.

(15) County health departments with local blood collection agencies should develop community education programs regarding appropriate self-deferral.

II. Public Health Education/Interventions

While traditional public health activities such as case reporting, serologic monitoring as well as testing for HIV constitute one arm of an effective AIDS prevention master plan, targeted educational efforts constitute the other critical strategy. Those Institute of Medicine recommendations relevant to education are as follows:

-> The major aim of AIDS education is modification of certain behavior with respect to sexual and drug use practices, such as unprotected anal and vaginal intercourse with those who are infected or at risk of being infected and sharing of injection equipment. In order to achieve this aim, educators and educational materials must be free to use clear and direct possibly colloquial, language that will be understood by those being addressed. The committee recognizes that the reluctance of governmental authorities to address issues of discussion of these matters. However, it believes that governmental officials charged with protection of public health have clear responsibility to provide leadership and guidance when the consequences of certain types of behavior have serious health consequences.

-> Discussion of alternative sexual behavior that provides at least a large measure of protection against transmission of the virus must be conveyed to those targeted for AIDS education. The proper use of condoms, in particular, should be stressed, and condoms must be widely and readily available to the public. It can no longer be assumed that unprotected heterosexual intercourse is safe. It probably is safe only in such
situations as a long-term exclusive relationships in which both partners have not engaged in risk taking behavior or where both partners test negative for HIV infection after refraining from risk taking behavior.

- Special efforts must be made to educate the population of intravenous drug users and their sexual partners about HIV transmission both by sharing of injection equipment and by sexual partners about HIV transmission both by sharing injection equipment and sexual intercourse. This population is one of the least cohesive subgroups in the nation, and innovative methods for reaching it must be developed.

- Although homosexuals, especially in urban areas are frequently portrayed as highly organized and easily reached, it would be a mistake to assume that all men who engage in homosexual activities perceive themselves as belonging to the homosexual community, or read the homosexual press.

- Blacks and Hispanics nationally comprise a disproportionate high percentage of AIDS cases, these groups require specially focused programs.

- Special attention must be paid to AIDS education for young people in schools and colleges, many of whom are entering periods of experimentation with sex and drugs. Frank discussion of behaviors that do and do not transmit HIV has become an urgent necessity for this target population.

- The public at large deserves to receive considerable attention about AIDS.

- Any form, either direct or indirect, discrimination against vulnerable high risk groups for AIDS should be discouraged and prohibited by state legislation and, where appropriate, by federal regulation and statute. In a positive manner, participation by representatives of high risk groups in policy making bodies should be encouraged where appropriate and practicable, and the help of public service programs such as health education, personal counseling, and hospital and home treatment service.

The primary modality for preventing further spread of HIV remains education. Educational efforts need to be targeted to high risk populations, the general population, as well as health care providers. Populations at highest risk in California remain gay and bisexual males, individuals with a history of intravenous drug use, hemophiliacs and individuals who received blood transfusions between 1977 - 1985. Minority populations are in special need of prevention efforts and special attention needs to be paid to sexually active young adults, including teenagers. Women of childbearing age who are sexually active with more than one partner, in particular need to be targeted, due to the possibility of transmitting the virus from an HIV positive mother to child. While there has been almost universal acknowledgment of the necessity of education for AIDS and some kind of outreach to
II. Public Health Education/Interventions (cont.)

the various populations, there has been much less agreement on the kind of message to be articulated or strategies to be pursued. Given the complexities of AIDS, the question of what exactly constitutes state of the art public health education, is also critical. These questions are made more complicated by the marginality, relative isolation of some of the populations, as well as the fact that many have been underserved historically. It is emphasized that the programs be tailored to needs of the various populations, that they be culturally sensitive and utilize individuals identified with the respective communities. Educational programs must encompass not only information dissemination, but also skill and community development.

An additional issue with regard to education efforts is that of methodology and concomitant with this, evaluation and assessment. Currently 42 California contractors are offering a variety of educational interventions that range form lectures, discussions and general information dissemination methodologies to street outreach efforts to skill building efforts. Still needed are evaluations and assessments as to which programs work best with which populations to greatest effect. Social science expertise in the areas needs to be utilized.

Targeted Populations

A. Homosexual/Bisexual Males; men who engage in sex with men.

Homosexual and bisexual males remain the population at highest risk in California consisting of 82% of the cases (6125) as of February 28, 1987. An additional 11% of cases were homosexual or bisexual males who used intravenous drugs. While evidence from a number of locales within the state (particularly in San Francisco) indicate a tremendous decrease in unsafe sex, still many homosexual and bisexual males remain at risk. This population may be disproportionately living in the southern part of the state where there has been less saturation with risk reduction messages, and skill building programs due to fewer county resources allocated to these activities. Particular sub-populations needing special efforts are: those men over the age of 45; those with a high school education or less; men in couples (research indicates a high portion of individuals in couples still engage in unsafe sex); bisexual males; men living in remote areas; men who do not belong to a community or a social group or who do not have a way of accessing safe sex information; minority males who may not be gay-identified.

1. Expand information dissemination and media attention to AIDS and safe sex guidelines among men who have sex with men.

   a. risk reduction ads in every gay newspaper, every issue for one year.
1. Expand information dissemination and media attention to AIDS and safe sex guidelines among men who have sex with men (cont.)
   b. posters/ads/condom displays placed in every gay business in the State.
   c. identification of gay leaders in non-metropolitan areas and their enlistment in major campaign to reduce seroconversion.
   d. enlist support of all major gay organizations in such a campaign.

2. Expand outreach and challenge programs such as "Stop AIDS" in every county having a significant gay population.

3. Expand skill development programs such as the Los Angeles Special Health Education Project (SHEP) and other community building efforts to each county having a significant gay or bisexual population.

4. Develop innovative pilot programs to reach those at highest risk: hustlers, individuals who are sexually compulsive, as well as other populations with special education needs such as men over the age of 45, couples, etc.

5. Develop outreach programs to individuals in rural areas of the state.

6. Develop two behavior science/health education resource centers, one in northern California and one in southern California to serve as clearing houses and centers for innovative program development and consultation.

7. Develop sensitive evaluation protocols utilizing quantitative and qualitative methodologies, to identify the most effective and cost beneficial interventions.

8. Develop special intervention programs to those homosexual men who are Black, Hispanic, Asian, or American Indian.

9. Develop programs to pilot prevention centers which could include risk reduction programs, immune testing/antibody testing/psycho-social support and referral.

10. Develop programs targeted to gay or bisexual men who have substance abuse problems whether with alcohol or other drugs.

B. Intravenous Drug Users

The California Department of Alcohol and Drug Programs estimates approximately 450,000 Californians use IV needles to shoot drugs (50% of the these chronically). Thus far in the epidemic approximately 13% of cases (1970 as of February 28, 1987) admitted a history of IV drug use. Key areas of intervention for AIDS education are Methadone treatment centers. In early 1987 some methadone treatment units were expanded in an effort to accommodate larger numbers of individuals seeking treatment but other efforts at getting individuals into treatment must be explored and yet more treatment slots need to be made available.
B. Intravenous Drug Users (cont.)

In addition to utilize methadone treatment centers, effort needs to be made to develop outreach efforts for drug users—both heroin and amphetamine users not yet in treatment.

Objectives for Intravenous Drug Users.

1. Street outreach program will be mounted to IV drug users to educate them about AIDS and to get them into treatment.
2. A media campaign will be undertaken to reduce needle sharing among IV drug users.
3. The number of slots for methadone maintenance and methadone detoxification programs will be increased 50% over the next 6 months.
4. All State and county professionals working in the area of drug abuse will receive 3 hours of inservice training on AIDS and will increase their knowledge and understanding about AIDS.
5. All state and county professionals working in the area of alcohol abuse will receive 2 hours of inservice training about AIDS and will increase their knowledge and understanding about the role alcohol can play in AIDS.
6. An AIDS IVDU resource, consultation and training center will be established to serve as a clearinghouse for persons doing outreach among IV drug users.

C. Women and Sexually Active Heterosexual Populations

Women must receive targeted information regarding risk of AIDS. Women attending family planning, prenatal and STD clinics need to be informed regarding the disease and testing on a confidential basis must be made available. Sexually active women and prostitutes and or women in the sex industry in particular must have risk reduction information.

While numbers of heterosexual contact cases are currently small (1% of the total), the numbers of cases are rising due to infection in sexually active heterosexual populations. Heterosexually active adults with multiple partners are a population at risk and need to follow safe sex recommendations. Outreach efforts should be developed among those who attend singles clubs, swingers groups and other associations of sexually active heterosexuals. County health officials and health educators be alert to prevention opportunities. Teenagers and college students should be targeted for special AIDS information programs.

Objectives

1. Every woman attending a prenatal or family planning clinic will receive 10 minutes of information about AIDS and where appropriate will be invited to be screened for HIV either anonymously or confidentially.
C. Women and Sexually Active Heterosexual Populations (cont.)

2. A statewide education and media campaign will be directed to women regarding AIDS; part of this campaign would be a special AIDS Awareness month for women.

3. Every woman or man attending as STD clinic will receive information about AIDS and appropriately be urged to be screened when for HIV.

4. Periodic assessment will be undertaken in a sample STD family planning and prenatal clinic as to the level of knowledge and understanding of AIDS among:
   a. clinic staff
   b. patients

5. Special health education efforts will be undertaken targeted to sexually active heterosexuals. Information will be disseminated to single's bars and heterosexual dating clubs in the state. Posters/ads will be placed in popular meeting places and information in newspapers, and sexually oriented bookstores.

6. An AIDS Awareness Campaign will be directed to college and university students.

7. Individuals testing HIV positive will be asked to voluntarily refer their sexual contacts for follow-up.

D. Minority Populations

Both Black and Hispanic populations are at elevated risk for AIDS--currently 10% of Californians AIDS patients are Hispanic and 9% are black. Special education, media and community outreach programs need to be developed with these populations as well as others such as native Americans and Asians. There should be identification of minority community leaders as role models and educational informants, as well as cooperation with clergy. Coordination with ongoing programs such as substance abuse and alcohol programs, family planning clinics and STD clinics should be undertaken.

1. A major media and information campaign will be undertaken in the current fiscal year directed to minority populations. Such a campaign would entail articles placed in newspapers, posters, and ads and billboards in ethnic neighborhoods and distribution of resource guide for minority and ethnic populations.

2. Neighborhood and community outreach programs will be implemented through state or county health departments; both urban and rural programs will be developed.

3. A pilot prevention/resource and "storefront" center will be established to serve as clearinghouse for information; antibody testing could be done in these centers.
D. Minority Populations

3. (cont.) education programs undertaken and referrals made to other clinics or agencies. One center should be established in a black neighborhood, the other in an Hispanic neighborhood.

4. Health care providers/clinics and HMO's serving minority populations will receive inservice about AIDS and will demonstrate increase in knowledge and understanding about AIDS.

E. Teenagers

Teens represent a special sub-population who need to be targeted for prevention purposes. Health departments, teen clinics, local AIDS information agencies and schools and recreation centers well (possibly including church groups, YMCA's-YWCA's) should establish working relationships and referral networks. All teens in all counties should be exposed to a minimum of 2 hours per semester of AIDS information for grades 7-12. Particular outreach needs to be made to teenagers out of school through street outreach and training through the Juvenile Justice System.

Objectives

1. Every teen clinic in the state will develop an AIDS information program; every teenager attending such a clinic will receive information about AIDS.

2. Every school nurse, social worker, librarian or counselor, working with teens in the State will receive at least 2 hours inservice training during the 1987-88 fiscal year and will increase knowledge and understanding of AIDS.

3. Develop a teen medical AIDS information campaign which will emphasize that AIDS is a teen health issue. Posters and information will be disseminated to schools, youth groups, teen gathering places.

4. Street outreach programs will be developed to reach homeless and street youths.

F. Prison Populations

Currently an increasing number of cases exist among state and county prison and jail populations in California. These populations are at risk for AIDS for a variety of reasons and must receive adequate risk education information. Inservice needs to be undertaken with prison and jail personnel. Such activities need to be monitored and coordinated through joint efforts between Department of Corrections, the Department of Health at the state local and at the county level between county health officials and jail personnel.
F. Prison Populations (cont.)

1. Inservice about AIDS will be undertaken in every county and state correctional facility. All jail and prison personnel will have received at least 2 hours of such training during the 1987-88 fiscal year.
2. Every individual incarcerated jail or prison will receive at least 10 minutes education about AIDS as part of being processed ongoing information dissertation processes will be developed.
3. Every jail and prison will have information on AIDS risk reduction including posters and pamphlets.
4. Condoms will be made available to inmates in prison and jail settings.

G. Prostitutes

While only a few cases exist among (female) prostitutes and women in the sex industry at present, they are high risk populations. Special efforts need to be undertaken to reach these individuals, direct them to appropriate clinics and screening facilities and educate them about safe sex practices.

1. County health departments in collaboration with the California Department of Health Services will develop intervention strategies targeted to these populations. AIDS outreach workers and STD investigators in collaboration with health educators will access these populations and provide them with safe sex information and the opportunity to be screened for HIV.
2. A special AIDS awareness campaign targeted to sexually active women and women in the sex industry will be undertaken. Pamphlets will be distributed in English and Spanish. By the end of FY 1987-1988 every prostitute and/or sex industry employee will know about AIDS and safe sex.

H. Hemophiliacs

As of February 28, 1987 there were 49 cases among hemophiliacs in California. AIDS health education efforts are currently undertaken by the California Hemophilia Foundation and medical centers where persons with hemophilia are regularly treated--education efforts directed to this population need to be continued and increased as deemed necessary.

1. Information dissemination particularly about safe sex should be undertaken.
I. Health Care Professionals

While many health care professionals in the major epicenters of the epidemic are familiar with AIDS, it has become clear that considerable gaps exist, in some surprising instances. A recent UCLA study indicated a low level of physician knowledge and expertise on the problem; similar surveys should be undertaken by the various health care professions in the state (nursing, social work, dentistry, chiropractor etc.) Programs for these providers, as well as first responders need to be developed.

1. A statewide training program for health care providers will be implemented, the goal being to improve prevention messages about AIDS, the importance of taking sexual histories, education about HIV, HIV testing and AIDS.

2. A statewide informational and training program will be developed for first responders, police and fire personnel.

J. General Population

The general population needs to be educated about the transmission of AIDS and how they are to protect themselves and others from infection. An AIDS awareness campaign should be undertaken. A special outreach should be made to the business community regarding AIDS in the workplace issues.

1. The Department of Health Services should mail to every family in the state a short pamphlet summarizing the Surgeon General's report on AIDS and providing referral information.

2. A California AIDS Awareness month should be planned with appropriate media exposure, posters, etc.

3. Hotlines for AIDS information and referral purposes will be continued and expanded as necessary.

4. All statewide business associations and local associations including Chambers of Commerce should develop AIDS briefings and programs such as AIDS in the workplace.

K. Other

In addition to specific educational programs, it will be essential that state and county health departments be able to hire appropriate personnel to direct and undertake these efforts. To this end the number of FTE's in the Office of AIDS, should be increased, including behavioral science/health educators, community outreach workers and investigators as well as managers. Some of there FTE's should be located in regional offices around the state so as to serve as consultants to county health departments.

1. The homeless of the State (400,000+ est.) are also at risk for HIV infection. An outreach program will be developed to target them.
Chapter 2, The Disease and the Epidemic

1. Recent data suggest that seroconversion is accompanied within a five year period by evidence of immunologic defects in more than 90 percent of individuals, including those who remain clinically asymptomatic.

   Furthermore, the development of characteristic abnormalities, as revealed by certain laboratory measures of the immune system, often occurs very rapidly after the appearance of antibodies.
   
   The longterm health significance of these early alterations in immune functioning are not yet fully appreciated, but they must be regarded as a cause for concern.

2. The typical time for transmission of the virus and seroconversion has been estimated to be six to eight weeks, based on observation of cases in which an isolated exposure to the virus was known to have occurred.

   This period is highly variable, however, with reported incidences of seroconversion occurring up to eight months after an isolated exposure to HIV.

   Isolated and unusual cases have been reported in which individuals remained seronegative for long periods of time although they were infected as evidenced by cultivation of virus from the blood. This possibility has implications for blood donation. (p.44-45)

3. Neurological complications are becoming increasingly recognized as an importance cause of the morbidity and mortality associated with HIV infection.

   As many as 90 percent of patients dying from HIV-related conditions have histopathologic abnormalities of the nervous system as postmortem examination, and the majority of patients have some clinical manifestation of neurologic disease during their lifetime. Of the HIV-related neurologic complications, dementia is among the most severe and disabling.
4. A wide variety of central and peripheral nervous system diseases are seen in AIDS patients.

About 30 percent of these patients develop opportunistic infections of the central nervous system (CNS), including toxoplasmosis, cryptococcal meningitis, and disseminated herpes infection. Some two to five percent develop CNS neoplasms, particularly primary CNS lymphomas, but also secondary lymphomas and metastatic kaposi sarcoma. Of patients with neurologic involvement, at least two-thirds develop a subacute encephalitis (mild brain inflammation), and twenty percent myelopathy, both of which are thought to be related to primary infections of the central nervous system with HIV. In addition, peripheral neuropathies develop in approximately 25 percent of patients.

5. Central nervous system involvement of HIV may lead to neurologic deficits that mimic many psychological problems, posing difficulties in diagnosis, and it may have a chronic course.

The occurrence of severely debilitating neurologic disease, especially dementia, will place a major strain on the health care system and on society as a whole in caring for affected patients.

6. There are many unanswered questions surrounding infection of the central nervous system by HIV.

They include the timing and frequency of infection, the amount of time that may elapse between involvement of the central nervous system and development of subacute encephalitis with dementia, and the primary site of infection in the central nervous system.

The answers to these questions will have major implications for the design of future therapeutic agents, which will have to cross the blood-brain barrier; for social, ethical, and legal issues involving AIDS; and for the planning of future health care for AIDS patients.

(p. 49)

7. Studies of homosexual men have identified couples with longterm, exclusive relationships in which one partner was infected with HIV and the other has remained uninfected over a considerable period, despite the seronegative partner's continued practice of anal intercourse.

Questions of possible individual variability in viral shedding and/or susceptibility need to be investigated further.
8. Although the virus has been isolated from semen and saliva, numerous studies have found no evidence that HIV is transmitted through homosexual men through kissing, oral-genital sex, oral-rectal sex, or mutual masturbation. HIV may be transmitted by these routes, but at relatively low efficiency. (p. 51)

9. The risk of HIV exposure for average recipient of packed red blood cells is estimated, on the basis of reasonable assumptions, to be fewer than one in 34,000.
Under slightly more optimistic assumptions, the risk should fall to fewer than 1 in 140,000. Under slightly more pessimistic assumptions, the risk rises to approximately one in 11,000.

10. With the risk of HIV transmission to blood recipients reduced by more than 95% through antibody testing, instead of 4,000 infected units out of 10 million used, the baseline calculations project the transfusion of about 100 infected units each year.
Since approximately half of transfusion recipients die of causes relatively soon after receiving blood, the number of infections directly relating from transfusion would be smaller.

11. Most of the current risk in blood transfusions relates to the possibility of blood donation during the pre-antibody phase of HIV infection.
These considerations reinforce the importance of continued self-selection by potential donors to exclude those who have engaged in high-risk behaviors. (p. 54)

12. Exposures through accidental needlesticks have resulted in fewer infections.
A CDC study of nearly 1,000 health care workers with accidental needlesticks show no clinical AIDS and only two seroconversions. In only one of these cases were there adequate data to clearly implicate transmission by the needlestick. There are isolated incidences of seroconversion after needlestick, including a case report of HIV transmission by needlestick from an African AIDS patient reported from England. In this instance, whole blood was thought to have been injected at the time of the needlestick. (p. 54)
13. AIDS and the fear of AIDS may reveal just how
tuous are the tolerance and acceptance of homosexuals. In
ting about AIDS, some have invoked explanations entailing retribution.
There have also been calls for the incarceration of homosexuals and for eliminating future tax dollars for AIDS research. Though such recommendations remain extreme, there still considerable institutionalized discrimination against homosexuals. In about half of the states, private sensual sexual activity between adults of the same sex is a criminal offense. The U.S. Supreme Court upheld right of states to pass such sodomy laws in an opinion issued in July 1986. (p. 59)

14. As of early 1986, about four percent, or almost one percent, of the more than 20,000 reported AIDS cases in the United States had occurred among health care workers. This percentage is similar to the proportion of the population employed in health care. In all cases fully investigated, risk factors other than being a health care worker were identified. (p. 63)

15. More underreporting may occur with nonhospitalized cases, partly because of physicians’ concern for maintaining confidentiality.
Such concerns undoubtedly lead to underreporting on death certificates, but this would have a more negative effect on research projects using death certificates than on national surveillance data. (p. 64)

16. All cases of AIDS in which no risk factor is identified are referred for further investigation to local health departments. Of those cases for which additional information is gained, most are reclassified into one of the known risk categories. Of the remainder, most stay in this "no identified cause" category because of incomplete information.

17. Because the CDC has not requested national reporting of ARC, no data on it are currently available from any source. Such reporting has not been requested for two main reasons. First, homosexuals have expressed concern that their health agencies will not maintain absolute confidentiality for such data (however, no personal identifiers are transmitted to the CDC). Second, there is nationally accepted definition of ARC and operational definitions can range from very mild signs and symptoms to very ill illness and death.
The Future Course of the Epidemic and Available National Resources.

1. But, in the judgement of the committee, other important resources in both the public and private sector have not yet become appropriately engaged or have addressed relevant problems inadequately.

The reasons for noninvolvement vary, but they include the following:

- Lack of awareness about the magnitude of the problem and the needs
- Slowness in responding to obvious needs
- Apparent reluctance or inability to pursue particular programs because of political, ideological, moral, or religious considerations, including the social stigma associated with some of the risk groups.
- Lack of appropriate recruitment efforts
- Lack of funds or other resources (e.g., facilities) for pursuing promising opportunities
- Lack of appropriate inducements to enter the field (e.g., stability of funding)
- Perceptions regarding the availability of reagents or other resources necessary for productive research
- Specific commercial disincentives (e.g., liability for vaccine-related injuries, uncertainty over market size and public health policy)
- Insufficient development of the basis research database upon which further commercial development might proceed
- Uncertainty with regard to federal agency responsibilities

Some of the impediments may be removed by relatively simple actions recommended in other parts of this report. Others are more complex and may require new mechanisms or more time to be reduced. (p. 93)
5. An integral aspect of an educational campaign must also be the wide dissemination about behaviors that do not transmit the virus. The public must be assured that ordinary standards of personal hygiene that currently prevail are more than adequate for preventing transmission of AIDS even between persons living within a single household; transmissions will not occur as long as one avoids the relatively short list of dangerous sexual and drug practices that have been identified. Unreasonable alarm about so-called casual contact with individuals perceived as possibly infected with HIV has produced many needless instances of discrimination and distress in the workplace and elsewhere.

6. Public education programs must aim at reducing this ignorance both in the general population and in the groups that will be particular targets of public education -- those at highest risk of contracting or transmitting the infection.

   In this regard, the committee is concerned about the Centers for Disease Control directive that empanels local review boards to determine whether materials developed for AIDS education are too explicit and in violation of local community standards -- this is the so-called "dirty words" issue. The result of such a process could be to cut off frank, explicit information from areas where it is needed the most -- in regions outside those urban centers that have large concentrations of homosexual men and IV drug users where awareness of the specifics of HIV transmission is already high.

   (p. 99)

7. For those already diagnosed with an HIV-related condition, information should be available regarding the kinds of treatment and volunteer services available. AIDS sufferers have been desperate for information about the testing of new drugs. Equitable access to drugs being tested in clinical trials will depend in part on HIV-infected individuals being aware of such endeavors. (p. 100)

8. Research is needed to identify the educational techniques that will be most effective in convincing users of the danger of needle sharing.

9. Also needed are ways to impress women users that infection can be transmitted by them to their fetuses with disastrous results. (p. 100)
10. Another goal of educational activities should be to replace the atmosphere of hysteria and irrational fear that is found in some quarters with rational information that will engender a level-headed attitude about the disease and one’s own risk of becoming infected with the virus.

Since many diverse groups must be educated, an early activity in this campaign must be the training of trainers. A network of individuals who are firmly grounded in the facts of the disease and who are adept at transmitting those facts in diverse settings should be established. (p. 100)

11. The most obvious targets for a campaign of education about AIDS are the presently identified high-risk groups: homosexual men, IV drug users, prostitutes, and sexual partners of those in high-risk groups.

Some efforts have already been made in this direction, but in general the only efforts with any claim to success have been those conducted by homosexuals through voluntary activist organizations. (p. 101)

12. It is important to communicate broadly the message that specific sexual practices involving infected persons are dangerous, not that homosexual men are at risk.

13. Heterosexuals, particularly those who have multiple partners, must be made aware of the risk to them.

14. Health care professionals must acquire and constantly update their store of information to be helpful to their clients (not only those suffering from clinical consequences of the infection but also the "worried well," both infected and uninfected) and to others with whom they are in a position to communicate.

15. Public officials, opinion makers, and the press represent other groups to which extensive education about AIDS must be targeted.

Their influence on matters of public policy is of prime importance, and misinformation among these groups can counteract the beneficial effects of many other educational efforts. (p. 101)

16. The youth of the nation, emerging into the sphere of sexual activity and becoming potential customers in the illicit drug trade, must be alerted to the existence of the disease and to its mode of transmission. (p. 101)

17. Blacks and Hispanics...require specially focused programs developed by health departments in areas having large black and Hispanic populations (p. 102)
18. The public at large deserves to receive considerable attention.

19. The lack of available treatment programs and facilities for IV drug users represents a serious problem. Drug treatment programs are greatly overtaxed at present, and a program that inspired widespread efforts at rehabilitation about IV drug users (to avoid AIDs) could swamp already strained facilities. Thus, efforts to achieve access to IV drug users must be coupled with realistic planning of ways to cope with success. (p. 103)

20. Health professionals -- doctors, nurses, health educators, public health officials -- are all important links in the educational process. They must be taught through professional associations, academic curricula, and continuing education so that they, in turn, can teach their patients and associates. (p. 103)

21. Among members of high-risk groups, counseling by peers is likely to be the most effective source of information, and such counseling should be available for those at risk. Government at all levels, not only local officials in certain high-incidence areas, must be willing to support and fund efforts to educate members of high-risk communities. (p. 103)

22. Many governmental efforts will necessarily address the general public rather than special target groups and will probably be limited to activities such as the distribution of pamphlets, placement of advertisements, and organization of telephone "hotlines." However, if nothing else is done, these general educational efforts will be grossly inadequate. (p. 103).

23. Government must prepare to fund targeted education through grants and contracts to private organizations that can communicate with special groups, in language appropriate to those groups, about relevant aspects of the disease. These include homosexual organizations (among which appropriate educational work has already begun in some areas), schools and colleges, women's groups, youth groups, prisons, prostitutes' groups, and any type of organization with access to the IV drug user population. (p. 103).

24. Although there is need for much greater involvement of foundations and private sector organizations with expertise in health promotion, such participation would not relieve the government of a fundamental responsibility in funding and implementing educational programs.
25. The most fundamental obligation for AIDS education rests with the federal government, which alone is situated to develop and coordinate a massive campaign to implement the educational goals outlined above. (p. 104)

26. In addition to measures of disease and incidence and knowledge about disease transmission as reflected in polling data, it will be crucially important to obtain reliable indicators of changes in the incidence of behaviors that involve risk of infection.

27. The launching of a massive and decentralized education program will have many unique elements, and it may involve a slow learning process with considerable trial and error. Rigorous evaluations of these education programs will be important if we are to learn from experience and thereby improve the programs. (p. 105)

28. The evaluation of AIDS education programs should be conducted by a group independent of those responsible for developing and implementing the programs, and the evaluators should provide for strong centralized oversight and quality control of their work. Past experience with large-scale, decentralized social research and evaluation programs indicates that research may be of poor quality without such oversight. (p. 105)

29. Understanding of this group [IV drug users] is critical, however, not only because they are the second largest group to have developed AIDS in the United States, but because they are the primary source for heterosexual transmission to their sexual partners and fetuses. Moreover, the large differences in seropositivity prevalence rates among IV drug users in different parts of the country mean that there is a tremendous opportunity to halt the further spread of infection by changing behavior among IV drug users. (p. 105)

30. Prevention programs targeted at reducing initiation into IV drug use may have to operate outside of school settings and focus on resisting social pressures to begin injecting drugs (similar to the cigarette-smoking prevention programs that focus on teaching skills to resist initiation into cigarette smoking). Such programs are undoubtedly more expensive than are the in-school programs, but they are no less critical. (p. 108)
31. The availability of treatment was significantly less than the demand for treatment even before the AIDS epidemic. Expanding the treatment system could significantly reduce IV drug use and the transmission of HIV. At a purely economical level, treating AIDS costs anywhere from $50,000 to $150,000 per case, whereas providing drug abuse treatment costs as little as $3,000 per patient per year in certain nonresidential programs (p. 109).

32. Although questions of priority are important, limitations on resources are not an acceptable excuse for not using drug abuse treatment to halt further spread of infection. (p. 109)

33. It is time to begin experimenting with public policies to encourage the use of sterile needles and syringes by removing legal and administrative barriers to their possession and use.

34. For at least the next several years, the most effective measure for significantly reducing the spread of HIV infection is education of the public with respect to modes of transmission of the virus. The present effort is woefully inadequate. It must be vastly expanded and diversified, aimed particularly at population subgroups such as those in which significant transmission has already occurred or can be anticipated, those in a position to influence public opinion, and those who interact with infected individuals.

35. The major aim of AIDS education is modification of certain behavior with respect to sexual and drug use practices, such as unprotected anal and vaginal intercourse with those who are infected or at risk of being infected and sharing of injection equipment. In order to achieve this aim, educators and educational materials must be free to use clear and direct, possibly colloquial, language that will be understood by those being addressed. The committee recognizes that the reluctance of governmental authorities to address issues of sexual behavior reflects a society reticence regarding open discussion of these matters. However, it believes that governmental officials charged with protection of the public health have a clear responsibility to provide leadership and guidance when the consequences of certain types of behavior have serious health consequences.
36. Discussion of alternative sexual behavior that provides at least a large measure of protection against transmission of the virus must be conveyed to those targeted for AIDS education.

The proper use of condoms, in particular, should be stressed, and condoms must be widely and readily available to the public. It can no longer be assumed that unprotected heterosexual intercourse is safe. It probably is safe only in such situations as a long-term exclusive relationship in which both partners have not engaged in risk-taking behavior or where both partners test negative for HIV infection after six months of refraining from risk-taking behavior.

37. Special efforts must be made to educate the population of intravenous drug users and their sexual partners about HIV transmission both by sharing of injection equipment and by sexual intercourse.

This population is one of the least cohesive subgroups in the nation, and innovative methods for reaching it educationally must be developed.

38. The total educational effort is the combined responsibility of all levels of government, and the private and philanthropic sectors must also participate significantly in this activity.

Government agencies that are reluctant to use direct and colloquial language in the detailed content of education programs must be able to accomplish their educational goals by contractual arrangements with private organizations not subject to the same inhibitions.

39. Special attention must be paid to AIDS education for young people in schools and colleges, many of whom are entering periods of experimentation with sex and drugs.

Frank discussion of behaviors that do and do not transmit HIV has become an urgent necessity for this target population.

40. One of the most difficult high-risk groups to deal with in the current AIDS epidemic is IV drug users.

More research, methadone and other treatment programs, detoxification programs, and testing and counseling services related to drug treatment programs are needed. If there are legal barriers to the implementation of such programs, these barriers should be dismantled.

41. Efforts to reduce sharing of injection equipment should include experimenting with removing legal barriers to the sale and possession of sterile, disposable needles and syringes.
42. AIDS education should be pursued with a sense of urgency and a level of funding that is appropriate for a life-or-death situation. Greatly expanded educational programs to effect behavioral change are necessary for high-risk groups and the public at large. These efforts should be supported not only by the government, but also by experts in advertising and the media. The total budget for AIDS education and public health measures from governmental and private sources combined should approximate $1 billion annually by 1990.

43. The decision of whether to be tested for antibody to HIV should remain a matter for individual discretion, given the array of potential risks and benefits that the test poses for those tested. Testing should be encouraged in light of its potential public health benefits. Mandatory screening of at-risk individuals is not an ethically acceptable means for attempting to reduce the transmission of infection. In addition, such a mandatory program would not be feasible in an open society.

44. Testing programs should be coupled with strong guarantees of confidentiality. Such assurances should perhaps be backed by punitive sanctions for unauthorized disclosure of antibody test results. The committee does not recommend compulsory reporting of seropositive test results.

45. The committee does not favor the establishment or the use of compulsory measures for isolation or quarantine of AIDS patients or seropositive persons in the general population. There may be need, however, to use compulsory measures, with full due process protection, in the occasional case of a recalcitrant individual who refuses repeatedly to desist from dangerous conduct in the spread of the infection.

46. Special precautions against the spread of AIDS and the AIDS virus may be necessary in closed populations, such as in prisons, jails, mental institutions, and residences for the retarded. Such measures should be applied with caution and only as clearly necessary and should not be used or cited as models for compulsory programs among the general population.

47. As a general policy, children with AIDS should be admitted to regular primary and secondary classes. The CDC guidelines are recommended for further reference in this area.
48. The committee believes that discrimination against persons who have AIDS or who are infected by HIV is not justified, and it encourages and supports laws prohibiting discrimination in employment and housing as formal expressions of public policy.

The committee also supports a federal policy to include AIDS as a handicapping condition under the federal law prohibiting improper discrimination against the handicapped.

49. Any form, direct or indirect, of discrimination against vulnerable high-risk groups for AIDS should be discouraged and prohibited by state legislation and, where appropriate, by federal regulation and statute.

In a positive manner, participation by representatives of high-risk groups in policymaking bodies should be encouraged where appropriate and practicable, and the help of organizations representing high-risk groups should be enlisted for public service programs such as health education, personal counseling, and hospital and home treatment services.

CARE OF PERSONS INFECTED WITH HIV

1. Actions should be stepped up to cope with the projected burden of HIV-related illness on the medical care system.

2. Although more research is needed to define the best approaches to care in different settings, experience thus far favors inpatient care by units or teams with a nursing and psychosocial support staff trained in AIDS care and integrated with outpatient and community-based staff.

3. For areas with a high incidence of HIV infection, where the financial impact of AIDS on health care systems will be great, attention should be given to the development of AIDS-dedicated outpatient clinics.

These units should have a staff of pertinent medical specialists, generalists, nurses and nurse practitioners, and specialists in psychosocial problems. Nurses and other professionals with responsibilities for AIDS care should receive training and social support.
12. Psychiatry staff must be able to assess patients' mental status so that the courts can determine competence in cases of dementia.

13. Additional funding will be necessary to provide sufficient chronic care facilities, partial hospitalization, outpatient units, drug rehabilitation centers, and home care to meet the psychosocial requirements of those with HIV-related disorders and to provide the additional staffing and support in existing facilities because of the unique psychosocial requirements of patients with HIV-related disorders.

14. Ways should be sought to facilitate the collection of information on all aspects of the costs of care for HIV-related conditions, especially AIDS and ARC, with complete confidence that patient confidentiality is ensured. Collection of information can probably best be helped by the design of specific diagnostic categories for AIDS and HIV-related conditions. Studies of the costs and effectiveness of alternative forms of care need to distinguish among various manifestations of HIV infection, including Kaposi's sarcoma, opportunistic respiratory and gastrointestinal infections, and neurological disorders.

15. All demonstration projects or other approaches to the provision of care for HIV-associated conditions should be designed so that it is possible to compare outcomes (longevity, quality of life) and thus the effectiveness of care.

The National Center for Health Services Research and Health Care Technology Assessment (possibly in conjunction with other organizations -- e.g., the Health Care Financing Administration) should commission an appropriate group to provide advice on the minimal data collection requirements to evaluate care modalities in demonstration projects or major centers providing care. Guidelines for data collection should, at a minimum, address (1) patient demographic data, (2) medical status at study entry, and (3) outcome measures (possible measures include longevity or the number of days spent out of the hospital as a surrogate for quality of life). Establishment of such guidelines is urgently required in light of the imminent funding of a number of major projects. Also, it is desirable to rapidly establish optimal modalities for cost-effective care before the anticipated large increases in the number of patients take place.

16. Funding for the health services research described above should be provided by the federal government, by the states, and by other organizations such as foundations and providers of health insurance.
Putting AIDS In Perspective ...

AIDS, a disease not long ago dismissed as the concern of gay men and drug users, is now, at last, taken seriously as a threat to the health of the nation as a whole. Discussion about condoms fills the airwaves and the private conversations of the young and sexually active. Proposals for widespread general acquired immune deficiency syndrome testing and new constraints on infected persons have appeared.

What has changed to make this so? For one thing, the number of reported AIDS cases has grown to almost 30,000. And while there has been no increase in the proportion of AIDS cases transmitted through heterosexual contact, now about 4 percent, public health officials expect that proportion also to grow — to perhaps 10 percent by 1991. But gay males and IV drug users remain at greatest risk.

Does that mean heterosexuals have no reason for concern? Of course not. Individuals who share needles or have unprotected sex with multiple partners, or a partner who has sex with others, are exposing themselves to a risk that did not exist a decade ago. Although the percentage of Americans infected with the AIDS virus is low — less than 1 percent — the potential consequence of a sexual contact with an infected person is large. The virus can be transmitted in a single encounter, many people who are infected with the virus go on to develop AIDS, and the disease is invariably fatal. That's certainly reason for caution.

But the statistics do mean that there's no reason to jump from concern into wild anxiety. Secretary of Health and Human Services Otis Bowen, with more metaphorical vigor than precision, recently compared AIDS to the Black Plague. But AIDS, unlike the plague, is not spread by insects or casual contact. To exaggerate the AIDS threat is to risk paralyzing Americans with worry or make them susceptible to showy but ineffective public health measures.

Among the expensive but dubious actions under consideration are proposals for widespread AIDS testing, proposals debated earlier this week at a Centers for Disease Control symposium in Atlanta. AIDS antibody tests for the general population — for couples seeking marriage licenses, patients at family-planning clinics and hospitals — would certainly give public health officials more information about how far the virus has spread. But much of that same information can be gathered more economically from sample surveys.

More important, proponents of wider testing have not shown, in most cases, how it would be useful in preventing or treating AIDS. In general screening, individuals who tested negative, the vast majority, would still have to behave cautiously to avoid becoming infected in the future. The knowledge gained from the test would not change that prescription. And until effective AIDS treatments are available, for people who tested positive there could only be advice to exercise caution to avoid spreading the disease, advice that all sexually active persons, infected or uninfected, should already be getting and heeding.

The one exception would be to encourage more testing where it's possible to prevent the spread of AIDS: from an infected mother to a child, either unconceived or unborn. Timing such testing to make it efficient or effective is difficult; marriage and childbearing are frequently years apart, many pregnancies are unplanned, and prenatal testing raises its own controversy about abortion. But such screening, even if not cost-effective, would educate would-be parents about the potential consequences of their behavior to the next generation. Otherwise, the money spent for widespread AIDS testing would be better used for getting out a message of concern and
... And The Methadone Stopgap

The state's attempt to curb the spread of AIDS among intravenous drug users by allowing more heroin addicts to be treated with methadone is a small but reasonable preventive step. The idea is that by relaxing the requirements for admission to drug treatment programs, more addicts can satisfy their cravings with methadone, which is taken orally, rather than by thrusting shared, unsterile needles into their veins, potentially spreading the deadly virus.

Although intravenous drug users currently account for only 2 percent of the known carriers of the AIDS virus in California, the percentage will undoubtedly grow. Nationally, the figure is 17 percent and California has about one-third of the nation's 750,000 opiate addicts. Moreover, research indicates that IV drug users are the primary transmitters of AIDS into the heterosexual community and that about 60 percent of the children with AIDS are offspring of IV drug users.

The effectiveness of methadone treatments in diverting addicts from heroin dependency remains debatable. But because of the extraordinary nature of the AIDS problem, it makes sense to expand the methadone program at least modestly to accommodate those who otherwise run a serious risk of contracting a deadly disease. It's also far less costly than widespread and mandatory AIDS testing and avoids the serious civil liberties questions the latter would raise.
March 17, 1987

Thomas E. Warriner, Undersecretary
Health and Welfare Agency
1600 9th Street, Room 450
Sacramento, CA 95814

Dear Tom,

As you know we have spent the last four months prioritizing the Surgeon General's and Institute Medicine's recommendations in order to develop model standards and programs for the prevention and treatment of AIDS in California. Shortly, we will be sending you a copy of our preliminary plan for your review.

Recently some very exciting clinical drug trial data has come to my attention. I have developed the following program which I have entitled "Lifeline". It represents what I believe to be a most significant prevention and treatment opportunity available to us for the following reasons:

* It will immediately accomplish our primary objective by offering a treatment modality that will encourage people at risk to determine their antibody status, thus slowing the spread of the virus and the progression of Human Immunodeficiency Virus (HIV) infection to AIDS.

* Compared to the suffering and expense of treating AIDS, it will be relatively inexpensive and therefore both humane and cost effective.

Up to now we have said that, in the absence of a vaccine or effective treatment, education was our greatest tool and that the knowledge of one's antibody status is a powerful preventive tool. The program we propose includes continued research and education and is the natural next step, given this exciting new knowledge. It will encourage people who perceive themselves at risk to be tested, receive education on prevention, and, if tested positive, to seek medical treatment early enough in the disease process for us to be able to prevent or delay opportunistic infections.
"Lifeline" is a large scale carefully controlled program to provide individuals infected with the HIV in California who show signs of immunological disfunction with Ribaviran, an antiviral agent which shows promise in delaying or minimizing the risk of developing life threatening HIV associated opportunistic infections. Department of Health Services experts estimate that approximately 300,000 to 500,000 Californians are infected by HIV. It is estimated that, in the absence of aggressive intervention, of those infected, 20% to 30% will go on to develop AIDS and die within the next 5 years. Therefore, in the absence of aggressive intervention, we will have between 60,000 and 150,000 Californians die of AIDS between fiscal years 1987-88 and 1992-3. At an average cost of $100,000 per case to care for each, the health care cost alone could be between $6 and $15 billion!

By aggressively intervening now, even if "Lifeline" costs $5 to $10 million* during the first year, it will pay for itself many times over.

During recent FDA supervised multi-centered, blinded, placebo controlled trials of Ribaviran at four centers that performed the AZT trials 163 men with pre-AIDS swelling of lymph nodes were divided into 3 groups given either a placebo, 600 mg. of Ribaviran per day, or 800 mg. per day. After 6 months the results speak for themselves:

<table>
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<tr>
<th>Clinical Progression To AIDS Among Treatment Groups</th>
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<tr>
<td>600mg./day</td>
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<td>-------------------------------------------------</td>
</tr>
<tr>
<td>AIDS 28 Weeks 6 (11%) 0 10 (18%)</td>
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<tr>
<td>24 Weeks 5 (5%) 0 8 (14%)</td>
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<td>EVENTS 28 Weeks 7 (13%) 0 17 (30%)</td>
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<td>24 Weeks 7 (13%) 0 15 (27%)</td>
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<td>LESS KS 28 Weeks 4 (7%) 0 9 (16%)</td>
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<td>24 Weeks 3 (5%) 0 8 (14%)</td>
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<td>OI 28 Weeks 4 (7%) 0 9 (16%)</td>
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<td>24 Weeks 3 (5%) 0 7 (13%)</td>
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Furthermore, the study demonstrated that Ribaviran's toxicity is low: only 3 of 163 participants required discontinuation of therapy (with AZT 1/5 of the participants required discontinuation and an undisclosed number required regular blood transfusions).

* (50,000 patients @ $1,000 to 2,000 per year).
Through instituting the "Lifeline" program we will initiate wider and longer trials to confirm these early findings, thus clarifying that Ribaviran delays the onset of AIDS in a significant percentage of those who maintain a dosage of 800 mg per day. It will further prove that, of the drugs tried and readily available, it is considerably less toxic and considerably less expensive to administer (see attachment A). All indications are, that even though it may not be a cure, and we can not yet be sure that it is effective for the long term, it appears that it buys us time to allow other research to be completed into alternate treatment modalities.

Ribaviran is licensed in over 25 countries other than the United States. Due to criticism of the manufacturer (See attachment B) and petty scientific squabbling, the FDA is being very slow in completing analysis of recent studies and may require unconscionable additional blinded, placebo controlled trials (see Attachment C).

Since the onset of AIDS many Californians have journeyed regularly to Mexico to buy the Ribaviran. Recently the Mexican Government doubled the price of the drug and we are beginning to see that ineffective counterfeit drugs bearing the same name are being sold, seriously endangering unsuspecting buyers. The longer we delay in making Ribaviran available to Californians, the more we will encourage large scale patient self medication without the opportunity for scientific observation.

What we propose is that California Department of Health Services show the courage, compassion, and common sense to continue our tradition of providing leadership in dealing with the challenges of AIDS by initiating the "Lifeline" program as described.

We propose to build safeguards into the program through which physicians, upon determining that a patient is infected with HIV and whose T-4 positive cell count is below a certain level, but who may not necessarily have developed significant symptoms, could prescribe Ribaviran. The physician could so by calling or writing a registration center, registering the patient, giving benchmark blood count and symptom information and proof of California residency. Upon registration, a central distribution point would ship a 60 day supply of Ribaviran to a local pharmacy where, upon verification of the identity of the patient, the pharmacist would distribute the drug.
Thomas E. Warriner  
March 16, 1987  
Page Four

The doctor would be required to re-examine the patient after 30 days and updated blood counts, symptom improvement, and toxicity data to the registration center before the next 30 day supply was sent.

By tying the ongoing supply of the drug to active reporting by the physician we will generate data very quickly which will demonstrate the drugs toxicity (if any) and efficacy.

ICN, the California company which manufactures Ribavirin has indicated an enthusiasm to be supportive of this program and has indicated an immediate ability to make significant doses available.

Soon the drug would be licensed and the program would be absorbed into the existing health care delivery system. Countless lives would be saved, the quality of many more improved, and hundreds of millions of dollars saved.

The wisdom of this project seems, to its author at least, appears inescapable.

I propose that the Department investigate the costs of implementing this program and that finance letters be drafted to the Legislature. I stand ready to bring together a team of scientists and physicians to assist.

Sincerely,

Bruce B. Decker  
Chairman, California AIDS Advisory Committee  
President, Health Policy and Research Foundation

BBD/dms  
Attachments
cc: Robert E. Anderson, M.D., California Department of Health Services
    Marcus Conant, M.D., Chairman, California AIDS Task Force
    Rex Ehling, M.D., President, Health Officers Association of California
    Gladden Elliott, M.D., President, California Medical Association
    William Filante, M.D., California AIDS Advisory Committee
    Martin Finn, M.D., Los Angeles County Department of Health Services
    Donald Francis, M.D., D.Sc., Centers for Disease Control
    Michael Gottlieb, M.D., University of California, Los Angeles
    Richard Hamilton, M.D., California AIDS Advisory Committee
    Peter Haseltine, M.D., University of Southern California
    Kenneth Kizer, M.D., M.P.H., Director, California Department of Health Services
    Phillip Lee, M.D., University of California, San Francisco
    Donald O. Lyman, Chief, Office of AIDS, California Department of Health Services
    J. Alan McCutchan, M.D., University of California, San Diego
    Dennis McShane, M.D., Stanford University
    Milan Panic, Chairman, ICN
    Michael Roth, M.D., California AIDS Advisory Committee
    Mervyn Silverman, M.D., American Foundation for AIDS Research
    Brad Truax, M.D., Health Policy and Research Foundation of California
    David Werdegar, M.D., Director, San Francisco Department of Public Health
    Warren Winkelstein, M.D., M.P.H., University of California, Berkeley
AIDS Drug AZT May Cost Users $10,000 a Year

By MARLENE CIMONS, Times Staff Writer

WASHINGTON — The first AIDS drug expected to be licensed could cost patients up to $10,000 a year, an amount that may be unaffordable for many — particularly those who have lost their jobs and health insurance because of the disease, a congressional panel was told Tuesday.

The drug, AZT, or azidothymidine, is expected to be approved for marketing within several weeks. Federal health officials, motivated by the urgency of the AIDS crisis, have moved to expedite licensing of the drug — the first shown to have a dramatic impact in prolonging the lives of AIDS patients — and have pledged to place other promising AIDS drugs on a so-called fast track.

Would Hasten Treatment

AIDS, we cannot ask the public to passively sit by when experimental drugs are being tested. We need to make these drugs available at the earliest possible time.

But the anticipated high cost of AZT may make it impossible for many AIDS patients to receive it under public health care assistance programs, federal officials told members of the House Energy and Commerce subcommittee on health Tuesday.

William Roper, administrator of the Health Care Financing Administration, testified that prescription drugs are an "optional benefit" under state Medicaid programs, with many of those states setting dollar limits on the amount they will reimburse.

"States may limit the number of drugs covered and the amount and scope of the benefit, for example, by restricting drug coverage to so many drug prescriptions per month," he said.

Further, he said, Medicare does not pay for drugs taken on an outpatient basis, as AZT would be administered. In California, however, a state law enacted last year requires that the state Medicaid program pay for any AIDS drugs approved by the FDA.

"Neglect to the Poor"

But Rep. Henry A. Waxman (D-Los Angeles), chairman of the subcommittee, said: "Giving patients nothing because they have no insurance and no money can be rationalized only as part of a system that provides health miracles to the wealthy and health neglect to the poor."

Since Oct. 14, AZT has been available free on an experimental basis to more than 4,000 individuals with AIDS.

The rationale behind the new FDA plan was the same as that which compelled the agency last fall to make AZT more widely available under a "compassionate use" treatment program. Last September, an independent board of scientists monitoring a clinical study of the drug decided that AZT had shown a dramatic impact in prolonging life and that medical ethics demanded that it be given to additional AIDS patients.

"Wider, Broader Approach"

The reaction you saw with AZT was a forerunner," Young said. "We are now proposing to make this approach wider, broader and more available than we ever did before."

However, the new proposal would require patients to purchase such experimental drugs. Young said the provision to sell the drug was made "to ensure that drug companies have enough incentive to make these drugs available" and to encourage competition by permitting smaller manufacturers "to test products that are extremely expensive to produce."

Young said the new regulations would provide "special criteria" that would apply to immediately life-threatening conditions, "recognizing that such patients are willing to accept a greater risk than normally would be the case." The regulations would also list different, though related, criteria for diseases that are serious but not immediately life-threatening.

"Bush said the regulations, which would become effective three months after the proposal is published for public comment, could enable individuals with life-threatening diseases to "obtain experimental treatment years earlier than is now the case."

AIDS: High Cost of Drug Cited

Continued from Page 1

for AZT through "the usual factors that influence pricing decisions," including costs of "developing, producing and marketing the drug, the high costs of research and the need to generate revenues to cover these continuing costs."

They noted that AZT may be replaced in the future by more effective therapies. "We don't know what will happen in the next year or two for new therapies — whether this will continue to be the drug of choice, we don't know," said T.E. Haigler Jr., president of Burroughs Wellcome.

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Pushing a Drug
ICN Takes Its Story
Of Way to Fight AIDS
Directly to the Public
Stock Price Rises, but FDA
And Scientists Are Critical
Of Handling of Virazole
Chairman Panic's Enthusiasm

BY EILEEN WHITE
AND MICHAEL WALDMOZ
Staff Reporters of The WALL STREET JOURNAL

The ICN Pharmaceuticals Inc. promotional film describes a study of the company's Virazole drug in men with the virus that causes acquired immune-deficiency syndrome. As the film closes, a grateful patient looks beseechingly at the camera. "My hope is that it is approved quickly," he says. "I hope the analysis of the data doesn't take six months, because I don't know if I have six months."

The film's none-too-subtle message seems clearly meant to prod the Food and Drug Administration into quick approval of the drug, which ICN says can forestall AIDS in people who carry the virus but haven't developed the disease. But the recent actions of ICN suggest that its main founder and chairman, Milan Panic, has more on his mind than the plight of AIDS victims.

While FDA staffers say more data must be provided before the drug can be sanctioned—and outside scientists say the company hasn't supplied data they need to evaluate the study—ICN has talked as though FDA approval were imminent. Since early 1986, Mr. Panic (pronounced PAHLN-ish) has been promoting the Virazole-against-AIDS story with "sneak preview" presentations to securities analysts, a series of positive press releases and, last month, a highly visible Washington, D.C., news conference announcing the company's claims about its AIDS study.

Since ICN began making claims about Virazole's use against AIDS a year and a half ago, its stock price has surged 134%. Shares of ICN's 46%-owned Viratek unit, which holds the rights to Virazole, have jumped about 258% in that period.

The soaring prices have helped ICN raise $436 million through stock sales and increasingly attractive convertible-debt offerings. The Costa Mesa, Calif., company is small as drug companies go—it earned $13 million on sales of $103 million in fiscal 1986—but the stock surge makes plausible Mr. Panic's stated plan to raise more than $500 million by year-end to take over a large drug company.

SEC Investigation

About six months ago, the stock movement prompted the Securities and Exchange Commission to open an investigation of possible stock manipulation and insider trading in ICN securities. An official of ICN says the agency is investigating the company's investment banker, PaineWebber Inc. See story on page 20.

ICN's publicity moves also raise broader questions about how best to release scientific information about drugs that are approved but possibly useful—as Virazole well may be. Some AIDS patients already are smuggling Virazole from Mexico, where it is sold legally for the equivalent of $28 for a three-day supply. Doctors worry that if a small drug maker successfully leapfrogged FDA procedures and normal scientific peer review by taking its pitch to the public, big, well-financed companies could be tempted to use similar tactics, perhaps resulting in premature claims about other experimental AIDS therapies.

In a study ICN has been publicizing, 163 men with a pre-AIDS swelling of the lymph nodes were divided into three groups and given either a placebo, a 600-milligram dose of Virazole or an 800-milligram dose. After six months, ICN says, AIDS had developed in 10 of the placebo group and in six of the next group, but in none of those getting the higher Virazole dose. The company and outside researchers who did the study call this strong evidence that the drug is active against the virus.

Two Get Disease Later

Other AIDS researchers find the effect promising but note that, in accordance with scientific practice, it must be confirmed by others; they also say it must last longer than six months to be of much use.

Since the study ended in November, two of the 800-milligram patients, though they continued taking this high dose of Virazole, have developed AIDS.

FDA officials advised ICN simply to keep quiet until the agency had reviewed its data—a review the agency says has top priority. Instead, ICN held its news conference last month. Company officials explain that they had to inform the test subjects of the results anyway and that once they did, word would begin to leak. They say they also made the announcement to quell volatility in the stock, which had been falling on rumors the drug didn't work.

Arnold Relman, the editor of the New England Journal of Medicine, says that "ICN was just plain outright wrong" in announcing its AIDS claims to the press. "That's not the way to release scientific information, and no market concern they..."

Please Turn to Page 29, Column 1

Continued From First Page
give justifies behaving that way," says Dr. Relman. Addressing the possibility of delay, he says that because of the urgency of AIDS, when a report of research on the disease is proposed to his journal, it gets an immediate review for publication.

Mr. Panic says the critics of ICN's promotional efforts are unfair, confusing "enthusiasm with exaggeration." He points out that respected Eastman Kodak Co. financed ICN's AIDS studies and is financing a $45 million, eight-year joint research venture with ICN into new drugs. Kodak holds 8% of the Viratek unit's common stock and 3% of ICN.

Whoever is right, this isn't the first time that ICN has drawn criticism and regulatory rebuke for its promotional campaigns. Since Mr. Panic, a 1956 immigrant from Yugoslavia, founded ICN in 1969, the record shows he frequently has used brash tactics to promote both its drugs and its stock. Over the years, he has tangled with regulators, shareholders, auditors and scientists.

"Militan can be crazy; it's just his way," says Lawrence Panitz, ICN's New York-based chief administrative officer. "You can't have a cohesive relationship with him... He just never thinks he's wrong." But Mr. Panitz insists his boss never says anything he doesn't believe.

John C. Hancock, a former ICN general counsel and now an outside legal adviser, adds: "I was always conscious of the need to make sure Mr. Panic understood the need not to overstate the prospects of the company."

Outside ICN, Mr. Panic has sought out well-placed political contacts and often held Democratic fund-raisers at his 42-room mansion in Pasadena, Calif. Among the prominent directors and advisers he attracted to ICN at various times were two men who headed the SEC and a former secretary of health, education and welfare.
Inside the company, Mr. Panic, who controls about 3.1% of the stock, “is one of those executives who are basically treating the company as their own field.” says Charles Bush, a former ICN chief financial officer. As part of a settlement of a shareholder suit in 1979, an audit committee of the board found that Mr. Panic owed the company $123,000 for personal medical and political expenses and for personal use of the company’s $50,000 jet and a lake Tahoe, Nev., vacation house. He paid it, but sympathetic directors awarded him $1,000 in back pay, despite the $17 million net loss ICN had posted the previous year.

Selling by Chairman

In late December of 1986, Mr. Panic sold 228,500 shares of an ICN subsidiary shortly after the parent’s directors had decided to buy back 500,000 of the unit’s shares. His sales began the day after the company announced the buyback. It appears that Mr. Panic’s net gain on the transactions was about $7.5 million. Asked about his stock trades, Mr. Panic says, “I think this is an unintelligent question.”

In 1977, the SEC accused ICN and Mr. Panic of having issued misleading financial projections in 1972. In several press accounts, the ICN chairman had given 1972 earnings projections that turned out to be about six times the actual figure. ICN and Mr. Panic paid and declined with the SEC, without admitting or denying any wrongdoing. When ICN’s auditors insisted on qualifying fiscal 1973 results because of pending shareholder suits related to the 1972 projections, he dismissed the auditors.

In 1970, ICN’s promotion of its pending license to market L-dopa, a drug for Parkinson’s disease, fueled a rise in the stock price. That enabled Mr. Panic to acquire about 40 companies, largely by exchanging ICN’s high-priced shares. But the market for L-dopa eased off after the drug was shown to have serious side effects. The ICN stock price fell enough that Mr. Panic had to compensate some of the previous owners of the acquired concerns because he had guaranteed them a minimum selling price for their ICN shares.

For promotional zeal, Mr. Panic’s first major ICN acquisition in 1967 appears classic. He obtained an option to buy for $6 million a pharmaceutical concern that would triple ICN’s annual sales. The option expiration date was approaching when an ICN scientist went to the annual meeting of the American Psychiatric Association to talk about a new, memory-enhancing drug known as ribavirin, the scientist recalls. When ICN’s stock price nearly doubled within about two weeks of the glowing presentation to the psychiatrists, a quick private stock sale at the higher price allowed ICN to raise the money to complete the acquisition. Ribavirin, however, was never even tested on humans. Mr. Panic says he decided not to spend any more money on it because he found out a rival was developing a similar drug.

Advent of Virazole

- With ICN mired in losses during most of the 1970s, Mr. Panic grew interested in Virazole. The drug, generically known as ribavirin, was developed in the late 1960s by Roland K. Robins, a biochemist and ICN co-founder. In the test tube, it has effects against a wide range of viruses, perhaps by blocking the action of chemicals they use to reproduce. Mr. Panic dubbed ribavirin Virazole and ICN has claimed at various times that it works against a list of diseases including influenza, genital herpes infection, measles, chicken pox, hepatitis, tropical fevers—and now AIDS.

- But ICN has had limited success in proving the drug both effective and safe. The firm didn’t gain FDA approval for any use until December 1985, and then only for hospital treatment in aerosol form against a lung ailment in infants. The story has some unusual aspects.

- For one thing, ICN, seeking to capitalize on its small victory, distributed a press kit touting Virazole. But the FDA, in a rare action, ordered the company to recall and correct the publicity material, asserting in a letter that it contained “false and misleading” information that “grossly exaggerated” the drug’s effectiveness. For instance, the press kit claimed that Virazole was so safe it could be given to premature infants “with no adverse reactions”.

- In fact, the FDA said, the drug may be “particularly hazardous” to premature babies.

Approval for Infant Lung Disease came after Vernon Knight, a highly respected researcher at Baylor University medical school in Houston, had found that the drug showed promise against flu complications when given in aerosol form. He developed a misting apparatus that averted potential side effects of the drug in pill form. His study was one of two that ICN submitted to the FDA.

Scientist’s Ties to Firm

But Dr. Knight’s financial ties to ICN have raised eyebrows in the scientific community. Perhaps the most striking tie involves options he was granted—many of them contingent upon the FDA’s approving some use of Virazole—to buy 37,500 shares of Viratek at prices of about $7 and $13 a share. With the stock now at about $64.50, his paper profit is about $2.1 million. He also serves as a Viratek director, receives $25,000 a year as a consultant and gets royalties for sales of the misting device.

When Dr. Knight and his Baylor team published their Virazole research, they disclosed that Viratek financed the studies. They didn’t mention his financial interest, although this is disclosed in SEC documents filed by ICN. The contingent options were granted after Dr. Knight had finished the last of his Virazole studies that were published, and no one questions his integrity.

Steven Mostow, a University of Colorado physician and virologist who was persuaded by Dr. Knight’s studies to research Virazole himself, says of the financial tie: “It’s the first I’ve heard of this. It’s crazy. The money can’t be worth the damage it could do his credibility.”

The FDA, which also wasn’t informed of Dr. Knight’s stake in ICN, doesn’t have any rules against such links, an agency official says. But, the official adds, “there’s a sense here that results from a scientist with a financial interest in a company might skew results.”

Dr. Knight acknowledges that some might see a conflict of interest. But he stresses that his relationship to Viratek has been approved by the head of Baylor’s school of medicine and that his research was checked by Baylor colleagues. He adds that ICN “has an interocean board chairman whose principles I don’t always agree with.”

Slow Progress In Lab Work

Although Virazole has shown remarkable promise in the test tube against a variety of viruses, ICN has baffled many researchers by its slowness to study the drug in clinical, or human, trials. The drug suffered an early setback in 1975, after American Cyanamid Inc.’s Lederle Laboratories ended a joint Virazole research venture with ICN. It is understood the company was concerned about side effects.

ICN then began its own research. But scientists who have worked with the company say that, over the years, ICN-financed studies of the oral form of the drug on human beings were often poorly designed, underfinanced and sometimes even abruptly ended because of budget cuts. In FDA documents, agency staffers say that ICN applications have contained numerous unsupported statements and inadequate data, and that the company has sometimes failed to provide information the agency requested. As a result, the FDA rejected Virazole in oral form for influenza, hepatitis and herpes infections in 1979, citing concerns about toxicity and lack of evidence that it worked.

Responding to the most recent application (in 1986) to use the drug against the flu, the FDA again asked for more studies, which the company says were begun last month. But ICN officials “have a long way to go before they can say [Virazole] is effective against the flu,” says Gilbert Schiff, a University of Cincinnati physician-researcher who has worked with Virazole. ICN “is fooling itself if it thinks it is close.”
Pushing a Drug: ICN Publicizes Experimental Way To Fight AIDS, and Company's Stock Price Climbs

Sold in Mexico
In the meantime, Mr. Panic promotes Virazole for AIDS. And longtime critics see history repeating itself in ICN's behavior in the torrid drug-company race for the right to sell a medication to the estimated one million to two million U.S. carriers of the AIDS virus. ICN's U.S. publicity for Virazole enhances its legal sales of the drug in Mexico, where until recently it gave a 60% discount to patients referred by a San Francisco AIDS-information group.

After the FDA gave a preliminary approval last September to the Burroughs-Wellcome drug AZT, ICN rushed out a press release on Virazole. The release boasted that the FDA had decided to award Virazole a classification that gave it "top priority" for review as a drug effective against AIDS. But the FDA actually hadn't made any decision; the classification is routinely given to any drug for which a company claims AIDS results, an FDA spokesman says.

Then came Mr. Panic's most controversial publicity stunt to date, the Jan. 9 Washington press conference. Sources close to the company said it was he who insisted on holding it—against the advice of the FDA, of ICN's outside public-relations firm, and of its director of regulatory affairs, a former FDA official.

Mr. Panic dispatched Robert Finch, a former HEW secretary who is a director of ICN and the chairman of Viratek, along with the firm's Washington counsel, former Indiana Sen. Birch Bayh, to press FDA Commissioner Frank Young for agency participation in the news conference. The FDA refused, saying its staff hadn't received enough details about the ICN study to make even a preliminary decision. "We told them we couldn't [participate] and suggested that they postpone it instead," says John Norris, deputy FDA commissioner.

Now, sources close to the FDA say the agency's review of the data isn't as optimistic as the picture the company released to the press. And they say a second ICN study of pre-AIDS patients, which recently ended, will show inconclusive results.

Other AIDS researchers are baffled by ICN's refusal to provide government and independent AIDS researchers around the country with details about its first study. For example, ICN hasn't furnished AIDS researchers with data, such as patients' red-blood-cell counts, considered necessary to evaluate the drug's effectiveness. Says Donald Armstrong, a physician who is the chief of infectious diseases at Memorial Sloan-Kettering Cancer Center: "None of us has been given an opportunity to evaluate what they've got."
Costa Mesa Drug Firm Object of U.S. Inquiry

By CARLA LAZZARESCHI Times Staff Writer

Federal regulators and a congressional subcommittee said Friday they are investigating allegations that a Costa Mesa drug company failed to notify authorities that its antiviral drug, Virazole, caused serious side effects among some infants.

The investigations by the Food and Drug Administration and a subcommittee of the House Energy and Commerce Committee are the latest in a string of setbacks for ICN Pharmaceuticals Inc.

The investigations come as the company is aggressively trying to convince regulators that Virazole may also have some effect against AIDS. And just last week the company confirmed that the Securities and Exchange Commission is looking into possible illegal trading of its stock.

Understandably Concerned

"Certainly the company is concerned," a spokesman said about the government probes. ICN Chairman Milan Panitz and President Lawrence Panitz were in Europe last week and could not be reached for comment.

(In trading on the New York Stock Exchange last week, ICN shares tumbled 25% to $17 from $22.625.)

According to a congressional staff member, the subcommittee on oversight and investigations received allegations earlier this month that ICN had failed to report adverse reactions among infants and children receiving Virazole for a rare and once-deadly lung ailment. The reactions are said to include fluid retention and heart failure.

The staff member declined to provide details of the allegations. The committee has asked the FDA for all its records on the drug and its use against the virus in infants.

In early 1986, the agency ordered the firm to recall and amend a press kit that it said contained "false and misleading" claims that "grossly exaggerated" Virazole's uses while "minimizing its side effects.

Although the subcommittee's inquiry is focusing on the drug's use with infants, the panel is also seeking FDA information on the drug's proposed use as a treatment for patients with AIDS symptoms.

Last year, ICN asked the FDA for expedited approval to sell Virazole on a "compassionate care" basis to pre-AIDS patients, and it was one of the first companies to conduct widespread clinical trials of its drug on patients with symptoms of the disease.

In a controversial move, ICN officials disclosed in a Jan. 9 press conference that the clinical trials showed that Virazole could delay the progress of AIDS when given to patients with early signs of the disease. They said the drug was "without significant side effects."
How FDA frustrates AIDS victims

By Dale Gieringer

Although researchers recently announced the first promising treatment for AIDS, the experimental drug AZT, many AIDS patients who are eager to try AZT still can't get it.

Food and Drug Administration regulations forbid the use of AZT — azidothymidine — except by patients who have been infected with a particular form of pneumonia and who meet numerous other medical criteria.

AIDS patients are understandably exasperated. "I know what the side effects of untreated AIDS are," says one. "Based on past experience, there's a 75 percent chance I'll be dead in two years. What's the harm with giving me some hope?"

Although AZT is a powerful, serious side-effect and only retards the disease — test studies were so encouraging that they were terminated early to let AZT be made more widely available.

Out of the nation's 13,000 AIDS patients, only 3,000 have qualified so far for the studies. The sickest patients are specifically excluded.

The FDA claims that it is premature to let other patients use AZT until further tests are conducted, but many doctors and patients feel differently. "It makes no sense at all," says one AIDS physician. "They let us use a lot of drugs that are a lot more toxic than AIDS drugs."

Agency regulations are designed to deny access to potentially life-saving drugs. Under present law, no new drug or medical device can be marketed until it has been officially approved — "safe and effective"— by the FDA.

FDA approval is a lengthy process that routinely takes years to complete. At least 70 percent of new drugs are approved in foreign countries before the United States approves them, often by many months or years.

Before approval, drugs can be used only in investigational studies that have been specifically pre-approved by the FDA through a procedure known as IND — for "investigational drug" — approval.

Because "investigational" drug requirements are stringent, time-consuming and expensive, access to unapproved drugs is severely limited. Of the nation's estimated 28,000 AIDS victims — living and dead — only a few hundred have been accepted in FDA-approved drug studies. Most of these have been "double-blind" studies: Half of the patients receive nothing more than a placebo.

"Occasionally, the FDA allows 'compassionate use' of investigational drugs for patients with otherwise hopeless conditions. However, the agency's definition of compassion is scarcely generous. Last year, the agency refused a compassionate-use permit for a temporary artificial heart in a 33-year-old patient dying of heart failure. Aside from AZT, no AIDS drugs are available on a compassionate-use basis."

Compassionate use involves burdened some red tape and paperwork. Thus, many physicians are reluctant to apply for it for their patients. In 1985, the Food and Drug Administration announced it would permit compassionate use of the drug isoprinosine, an immune booster of possible benefit for AIDS. But the manufacturer, Newport Pharmaceuticals, could not afford to make it available because the cost of complying with FDA regulations came to some $2,000 a patient. In comparison, a year's supply of isoprinosine could be bought from Newport's Mexican subsidiary for only $300.

The perverse result of the FDA's "protection" is that American patients have been forced to seek treatment abroad. Hundreds of AIDS victims have been going to Mexico for isoprinosine and ribavirin, another unapproved drug with some potential for mitigating AIDS.

Reform is needed to allow patients freedom of access to experimental drugs. The basic idea should be to legalize use of unapproved drugs so long as patients receive appropriate warnings to insure informed consent. Unapproved or hazardous drugs should be clearly distinguished through label and oral warnings, with signed informed consent statements where necessary to assure that no one is exposed to them involuntarily.

Informed choice would enhance drug safety by giving consumers better information about drug risks. Americans are now among the least well-informed drug consumers in the world. Dangerous prescription drugs are commonly sold without any label, instructions or warnings. There is reason to think that the misuse of existing old drugs is a greater health hazard than exposure to new, untested ones. Under an informed-choice system, consumers of new and old drugs alike would receive suitable warnings and usage instructions.

Defenders of the present system argue that FDA restrictions are needed to protect consumer health: In fact, however, there is no scientific evidence that the FDA approval system is either safe or effective. Economic studies have repeatedly found that the FDA is overly cautious. At present mortality rates, a mere two-month regulatory delay in development of an effective AIDS cure could cost 1,000 lives.

Congress recently passed legislation allowing FDA-unapproved drugs to be exported to foreign countries. If foreign consumers should have the right to get such drugs, so should Americans.

A country that honors free choice in religion, speech and politics should also honor free choice in medicine. Victims of incurable disease should not be held hostage to the tyranny of government bureaucracy.
We are in the process of reviewing the Institute of Medicine's Report on AIDS and will be submitting to you by February 1, 1987 summary reports on the priority considerations in two major areas: treatment and prevention.

Father Albert Ogle, formerly Director of Planning of AIDS Project Los Angeles has been retained to coordinate the treatment plan preparation. His experience assembling the Los Angeles Robert Wood Johnson proposal uniquely qualifies him to prepare the statewide treatment recommendations.

Dr. Michael Gorman, formerly of the CDC, has been retained to coordinate the prevention plan preparation. His work at the CDC, the Los Angeles Robert Wood Johnson project, and most recently at the Rand Institute, uniquely qualifies him to prepare the statewide treatment recommendations.

One of the priorities in the Institute of Medicine's Report is creating comprehensive, coordinated and collaborative Federal, State, local, and private sector programs. This Foundation has created the forum where this will happen for California in the most cost effective and efficient way.

Given that we have policy makers from the Federal, State, local and private sector agencies involved in the preparation and presentation of the plan, we feel that it will be a highly credible document.

Once the plan is developed and agreed upon, each funding entity can look to their resources to see what portions are currently funded, what budgeted programs apply to portions not funded, and what gaps will remain to be filled by the creation of new programs. Only by this kind of collaboration, given limited resources, can we, cost effectively and humanely deliver the necessary treatment systems while simultaneously preventing further infection.
Assuming that 600,000 Californians are now infected with the virus and that 30% will die from infection in the next five years at a cost of approximately $100,000 each, the health care delivery system of public assistance and private insurance will be hit with an $18 billion bill.

At the same time that we are paying for the treatment of those whose infection we did not prevent over the past five years, we must be preventing the infection of those no yet infected or we will be burdening future generations of taxpayers and stockholders with catastrophic needs.

We are encouraged by the initial positive response of all sectors of the community to this initiative. With leadership from the Public Health experts in California have assembled a powerful creative partnership.

Background

The Health Policy and Research Foundation was founded in the Spring of 1986 at the suggestion of Kenneth Kizer, M.D., M.P.H. Director, of the California State Department of Health Services. Recognizing the potential impact of AIDS on California's economy and the relatively recent funding interest by a broad base cross section of government agencies, foundation, corporations, and major donors, a three part planning program called "CALIFORNIA's WAR on AIDS" was initiated: first, to identify all AIDS related projects funded here in California; second, a needs assessment in order to avoid duplication of effort or ignoring of needs; and third, the ongoing coordination of the various programs. The Foundation's Board of Trustees and Executive Evaluation Committee represent the most eminent and involved AIDS sensitive physicians, researchers, educators, public officials, service providers, civic leaders, and professionals ever assembled.

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Board Member, Economic Opportunities Council
Member, University of California, San Francisco, AIDS Health Project
PROJECT SCHEDULE

Wednesday, January 21, 1986

Board of Trustees meeting - Los Angeles

Review priorities and approve for distribution to the Evaluation Committee

Friday, January 30, 1987

Mail Treatment and Prevention prioritized Institute of Medicine recommendations to Co-Chairs and Evaluation Committee with request for feedback by February 19, 1986.

Monday, February 23, 1986

Revise documents for presentation.

Thursday, February 26, 1986

Board of Trustees meeting - San Francisco

Co-Chairs and Evaluation Committee meeting and hearing - San Francisco. Presentation by staff of revised Prevention and Treatment priorities discussion of process to develop plans.

Friday, March 20, 1987

Board of Trustees meeting - Sacramento

Review proposed Treatment and Prevention Plans for distribution to Co-Chairs and Executive Evaluation Committee.

Friday, March 27, 1986

Mail Treatment and Prevention Plans to Co-Chairs and Executive Evaluation Committee with request for feedback before April 17, 1987.

Monday, April 20, 1987

Revise Plan for presentation

Friday, May 1, 1986

Board of Trustees meeting - Los Angeles

Co-Chairs and Executive Evaluation Committee meeting and hearing - Los Angeles. Presentation by staff of revised Treatment and Prevention plans and budgets - discussion.
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Assisted in the founding, American Foundation for AIDS Research
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Epidemiologist, Public Health Service Officer, Epidemiologist Intelligence Service, Centers for Disease Control
Faculty Member and Facilitator, American Public Health Association Workshop on Strategies for Collaboration on AIDS Issues
Project Coordinator, AIDS Prevention/Health Education Project, Division of Health Education
HEALTH POLICY AND RESEARCH FOUNDATION

BUDGET

CALIFORNIA'S WAR ON AIDS

Oraganizational Expenses
(November, 1986 and preceeding months)

<table>
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<td>Travel/meetings</td>
<td>1,500</td>
</tr>
<tr>
<td>Supplies/communication</td>
<td>1,500</td>
</tr>
<tr>
<td>Move in/open office</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>$7,500</strong></td>
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Operational Budget
Monthly
(December 1, 1986 - May 31, 1987)

<table>
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<tr>
<th>Item</th>
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<td>Executive Director (1/2 time)</td>
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<td>Administrative Assistant (full time)</td>
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<tr>
<td>Equipment rental</td>
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<tr>
<td>Phone</td>
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<td>1,000</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>$11,750</strong></td>
</tr>
</tbody>
</table>

**TOTAL COST** $78,000
December 3, 1986

Bruce B. Decker, President
Health Policy and Research Foundation
7985 Santa Monica Blvd., #109-251
Los Angeles, CA 90046

Dear Bruce:

I have received your letter of November 26 regarding the "California War on AIDS." I agree wholeheartedly that a coordinated Federal, State and local response is essential if we are to manage the health service and health financing crisis posed by the epidemic.

I understand that the Foundation wishes to orchestrate a State-wide needs assessment and planning effort. However, it is not entirely clear from your letter what role the Foundation proposes to play; what kind of collaboration you envision from DHHS, DHS, HOAC, CAAA, and UC; whether the Foundation is really the most appropriate organization to undertake such an effort; or what you are asking me to endorse.

Initially, my reaction focused on two issues:

(1) Wouldn't such an effort unnecessarily duplicate the work of all the new staff of the Department of Health Services?

(2) How could a Foundation whose governing board is so heavily male (83%), gay/lesbian (92%) and white (at least 92% and probably 100%) establish enough credibility among women, heterosexual men and racial/ethnic minority groups to secure their necessary cooperation in such an effort?

Upon reflection, I have added several questions to the list:

(3) What has been done to insure "collaboration with the US Department of Health and Human Services, the California Department of Health Services, the Health Officers Association of California, ..." and what form will that collaboration take?

(4) You mention an Executive Evaluation Committee which will meet once in February and once in April. Who else have you invited to serve on the Committee, what authority will the Committee have in determining the content of the final report and how will the Committee relate to the Foundation's Board of Trustees? How will the Committee relate to you in your capacity as Acting Executive Director? How soon will the regular Executive Director be on board? (I am concerned about the propriety of having the holder of a salaried position in a non-profit corporation serve concurrently as president of the governing board.)
You speak of the Foundation's staff gathering data and drafting the report. Experience with other researchers suggests this means your staff will ask my staff to gather data which your staff will incorporate into a report. What, precisely, do you have in mind for my staff? We are all seriously overextended and I cannot glibly assume additional responsibilities for them.

What role does the Foundation envision for itself after this report/plan is produced in April? Will the Foundation eventually be competing with the San Francisco Department of Public Health for State or Federal funding of audience assessments, information and education, medical and chronic care, or related support services?

I would appreciate very much your responding to these concerns in writing. I do not think I will be in a position to discuss your proposal and invitation with Dr. Werdegar until I have heard from you again.

Thank you for your consideration.

Sincerely,

Jeffery W. Amory, Director
AIDS Office

CC. Dave Werdegar
Jim Foster
Steve Morris
Jim Milford
Larry Bush
November 26, 1986

Mr. Jeff Amory, Special Deputy/AIDS
San Francisco
Health Department
101 Grove Street
Room #323
San Francisco, California 94102

Dear Jeff,

Your role in leading California's model AIDS response program is widely recognized. I, and many others, genuinely appreciate the commitment you have made to finding humane, logical and cost effective solutions to the complex problems AIDS presents.

The Surgeon General's report, combined with the National Academy of Science report and the Proposition 64 campaign, clearly illustrate the next great challenge we face: that is the need to, as the PHS/Coolfont report concludes:

"develop a coordinated Federal, State and local response to manage the health service and health financing crisis posed by the escalating AIDS epidemic. This response must reflect the pluralistic character of the American health care system, and must involve the coordinated participation of public, private, and voluntary sectors as well as ambulatory, in-hospital and long term care providers."

We, working in collaboration with the U.S. Department of Health and Human Services, the California Department of Health Services, the Health Officers Association of California, the California Association of AIDS Agencies, and the University of California AIDS Research Task Force, among many others are embarking on the development of a long term strategic plan in order to maximize the resources available in meeting current and future AIDS related needs here in California.

We are calling it "CALIFORNIA'S WAR ON AIDS". We will canvass resources available and anticipated needs making recommendations regarding how each sector of our society can help fill future financing and resource needs. We will look at the needs for training, continuing education and psychological support for institutional and community based research, mental health, prevention, and treatment providers. At the same time we will look to develop comprehensive delivery systems for those at risk and suffering from AIDS in each of these four major areas.

In addition to promoting extensive prevention education programs, our particular concern will be the development of organized consortia of service delivery systems responsive to the care of AIDS patients including all the necessary components of ambulatory, hospital,
mental health, dental health, counselling, home health care and hospice care.

In a dramatic demonstration of the need for comprehensive strategic planning, the Public Health Service estimates that the direct health care costs of Californians with AIDS will be between $2 to 4 billion in 1991. (We suspect it will be far greater in that the estimate is based on a $46,000 per patient calculation. Not only do we experience a higher cost today, but the estimate is based on 1986 dollar values). With 25% of the estimated 145,000 national cases here in California (71,000 patients alive and 74,000 new 1991 diagnosed cases) plus an estimated 20% under-reporting of cases, AIDS will represent between 1.2% and 2.4% of the expected total of California's personal health care expenditures in 1991.

These estimates may have to be revised upward by 50% because of the increased need for care for the large population of patients with conditions associated with other infections and significant non-medical care costs necessary for the management of these illnesses.

Only by maximizing our resources will we be able to meet these incredible needs. Humane and cost effective care will require strategic planning and the development of community based health and social services support systems to reduce costs and enhance care.

We ask you to join our "WAR" by agreeing to serve on our Executive Evaluation Committee. The Committee will meet twice in the first sixth months of 1987; once in February, where we will present our report of all AIDS programs funded in California, and in April, where we will present our report on anticipated needs for AIDS prevention, mental health, treatment and research programs for fiscal year 87/88. Our staff will gather the data and we will provide you with advanced copies so that nothing is released without your advanced approval.

Your endorsement of our efforts and the support of the San Francisco Health Department is vital to the success of our efforts.

Sincerely,

Bruce B. Decker
President and Acting Executive Director

BBD/dms
Enclosures: Board of Trustees
Statement of Purpose
Statement of Purpose

Recognizing the potential impact of AIDS on California's economy and the relatively recent funding interest by a broad base cross section of government agencies, foundations, corporations, and major donors, a three part planning program seems prudent: first, to identify all AIDS related projects funded here in California; second, a needs assessment in order to avoid duplication of effort or ignoring of needs; and third, the ongoing coordination of the various programs.

The Health Policy and Research Foundation was founded to do so in the Spring of 1986 at the suggestion of Kenneth Kizer, M.D., MPH, Director of the California Department of Health Services. It's Board and Advisors represent the most imminent and involved AIDS sensitive physicians, researchers, educators, public officials, service providers, civic leaders, and professionals ever assembled.

The No on 64/Stop LaRouche campaign, the Surgeon General's report and the National Academy of Sciences reaffirm that cohesive and strategic planning are critical.

Continuing California's tradition of leadership in meeting the challenges of AIDS, the Foundation is launching the much needed report preparation of all Federal, State, local and private sector AIDS programs and subsequently a report of anticipated needs resulting from the analysis. Subsequently, the Foundation will also be launching a corporate involvement campaign among California's major employers to assist them in dealing with AIDS issues.

Recognizing that funds available are limited and that needs will increase greatly, the Foundation is committed to maximizing the impact of programs through coordination, cooperation and the avoidance of unnecessary administrative and overhead expenses.

Working heavily with volunteers, the Foundation has a minimal staff and overhead expense. The small investment required for funding it's activities will be worth it, and will pay off many times over during coming years, helping to maximize funds available and minimize the fiscal and emotional impact of AIDS on all Californians.
Health Policy and Research Foundation
Board of Trustees

Bruce B. Decker, President
Los Angeles
Founder and Finance Chairman, No on 64/Stop LaRouche Campaign
Chair, California AIDS Advisory Committee
Chair, California Strategic Planning Commission
Assisted in founding, American Foundation for AIDS Research
President, Concerned Americans for Individual Rights

Stan Hadden, Secretary
Sacramento
Special Assistant to State Senate President David Roberti
Member, California AIDS Advisory Committee
Member, California Strategic Planning Commission
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Member, Sacramento Mayor's AIDS Task Force
Board President, Sacramento AIDS Foundation
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Larry Bush
San Francisco
Special Assistant to Assemblyman Art Agnos
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Member, California Strategic Planning Commission
Member, Executive Finance Committee-No on 64/Stop LaRouche Campaign

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Clinical Psychologist, Private Practice
Founder, Municipal Elections Committee of Los Angeles (MECIA)
Advisory Board Member, Southern California CARES Program
Fundraiser for MECLA and AIDS Project Los Angeles
Member, AIDS Task Force, Gay and Lesbian Community Services Center
Member, California AIDS Strategic Planning Commission
Consultant, Stop AIDS, San Francisco
Co-Creator, The Advocate Experience
Member, Executive Finance Committee, No on 64/Stop LaRouche Campaign

Georgia Garrett Norris, Esq.
Santa Ana
Attorney, Private Practice specializing in gay/lesbian issues
Member, Lawyers for Human Rights
Member, American Civil Liberties Union
Founding Member, Elections Committee of County of Orange
Board of Directors, AIDS Services Foundation
Member, Executive Finance Committee, No on 64/Stop LaRouche
Health Policy & Research Foundation of California

To: Executive Evaluation Committee Members, Co-Chairs, and Observers

From: Bruce B. Decker, President

Date: April 2, 1987

Re: Draft of California AIDS Prevention/Treatment Plan

With special thanks to Don Francis, M.D., D.Sc. and Bob Anderson, M.D., acknowledgement to it's authors, Mike Gorman, Ph.D., M.P.H. and Rev. Albert Ogle, and with particular gratitude to our patient and hard working assistant David Smith, we enclose the preliminary draft of our proposed California AIDS Prevention/Treatment Plan.

The past 5 months have been particularly challenging and we are proud of our work. Not so proud, however, as to not recognize that with your evaluation and input it will be a better document.

Please read the plan, comment on it and have those written comments to us by 5:00pm on Wednesday, April 22nd.

Please plan to attend our presentation of the plan for it's first public discussion on:

Friday, May 1, 1987 1:00pm-5:00pm
State of California Building
107 S. Broadway (at First Street) Rm. 1138
Downtown Los Angeles

It is important that you attend to participate in the discussion and endorsement of the plan.

I view this document as turning point in our "War Against AIDS". We are moving from being reactive to being proactive. I hope that you are as proud as I am to be part of it and I hope you will take your responsibility to it's quality very seriously by commenting on it and joining us on May 1st.

Sadly, a major part of our funding has not come through so without additional support we may not be able to complete the process of finalizing this great plan. If you know of any possible funding sources, I have borrowed or loaned all the money used to date. It must be repaid along with the funds to keep us going for these last two months.

If you think this is a worthwhile project and that it is important that it be completed, please let me know how you can help.

Thank you again for your support and participation

7985 Santa Monica Blvd., #109-251, Los Angeles, California 90046  (213) 278-9355
Dennis McShane, M.D.  
Menlo Park

BAYMEC Liaison
Member, Executive Finance Committee, No on 64/Stop LaRouche Campaign
Member, California AIDS Strategic Planning Commission

Steve Morin, Ph.D.  
San Francisco

Member, Northern California Executive Finance Committee
No on 64/Stop LaRouche Campaign
Chair, California Council on Mental Health
Chair, State Psychological Association
Member, California AIDS Strategic Commission
Member, Department of Mental Health AIDS Task Force

Dick Pabich  
San Francisco

Northern California Coordinator, No on 64/Stop LaRouche Campaign
Member, Northern California Executive Finance Committee
No on 64/Stop LaRouche Campaign
Member, California AIDS Advisory Committee
Administrative Analyst, University of California, San Francisco

Michael Roth, M.D.  
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Vice Chair, California AIDS Advisory Committee
Member, California AIDS Strategic Planning Commission
Staff, AIDS Center, University of California, Los Angeles
UCIA Men's Study Advisory Board

Peter Scott, Esq.  
Los Angeles

Founder, Municipal Elections Committee of Los Angeles (MECIA)
Media Director, No on 64/Stop LaRouche Campaign
Board of Directors, National Gay Task Force
Co-Manager, No on 6 Campaign
President, Mixner & Scott, Inc.
Co-Chair, California AIDS Strategic Planning Commission
Former Board Chairman, AIDS Project Los Angeles

Lillis Stephens  
San Diego

Chair, Hemophilia Council of California
Member, California AIDS Advisory Committee
Member, California AIDS Strategic Planning Commission
President, Hemophilia Association of San Diego
Member, San Diego County AIDS Task Force
Member, Committee on Juvenile Justice, San Diego

Tim Wolfred, Ph.D.  
San Francisco

Executive Director, San Francisco AIDS Foundation
Member, California AIDS Strategic Planning Commission
Board of Governors, Community College District, San Francisco