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California's War on AIDS

Health Policy and Research Foundation of California

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of California

CALIFORNIA'S WAR ON AIDS

California AIDS Prevention / Treatment Plan 1987-1991
dedicated to the memory of Professor Beverlee A. Myers

May 1, 1987

STATE OF CALIFORNIA
SENATE
SACRAMENTO, CALIFORNIA 95814

DAVID ROBERTI
PRESIDENT PRO TEMPORE

May 21, 1987

Dear Colleague:

On March 5, 1987 the California Senate and the Assembly met in a historic Joint Session to hear from U. S. Surgeon General C. Everett Koop. The Surgeon General was asked to address the California Legislature because he has taken dramatic action to fight AIDS.

Over the past six months the recommendations contained in both the Surgeon General's Report on AIDS and the National Academy of Sciences report Confronting AIDS have been prioritized and evaluated by the Health Policy and Research Foundation of California. I was pleased to be a part of the Executive Evaluation Committee which participated in the review of the enclosed report, California's War on AIDS.

For the last several years Assemblyman Vasconcellos has convened a task force to make recommendations on state funding for AIDS programs. This task force reviewed California's War on AIDS and concluded that $165 million would be the ideal level of funding for California's fight against AIDS in the coming year. Unfortunately, the state is not in a fiscal position to fund a program at this level. However a Senate subcommittee has approved a scaled down figure of $65.5 million as recommended by the AIDS Budget Task Force.

More money and more creative responses to this crisis are needed. I encourage you to review this document, and to join the effort to ensure that funding for the fight against AIDS escalates substantially.

Sincerely,

David Roberti

DAVID ROBERTI

DR:sh

Health Policy and Research Foundation
of California

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DEDICATION

This report and planning effort were inspired by Professor Beverlee A. Myers, former Director of the California Department of Health Services (1978-1982) and Professor of Health Services, University of California, Los Angeles School of Public Health.

After finishing her graduate work in public health at the University of Michigan Dr. Myers spent 11 years working with the U.S. Public Health Service in Washington, D.C. ultimately to become Director of the Office of Planning and Education and Assistant Secretary for Health. Following this appointment, she undertook the difficult task of Deputy Commissioner for Medical Assistance in the New York State Department of Social Service for 3 years. This period was followed by several years as a consultant to the U.S. Senate and as a lecturer at the University of Michigan School of Public Health. Dr. Myers returned to California in 1978 and became head of the Division of Health Services at U.C.L.A. in 1984.

Her career was marked by a monumental dedication to public service and to the provision of high quality medical care to all citizens. She was particularly concerned with the health of underserved populations and of addressing the long term health needs through community based planning efforts. Her involvement and interest in AIDS began in 1983 when she saw the implications of the epidemic, its impact on health care and the needs for public health prevention. Out of her concern she became a catalyst to assess needs for health care for AIDS patients. Dr. Myers was closely involved in the development of Los Angeles County's proposal to the Robert Wood Johnson Foundation, the U.S. Public Health Service for AIDS planning and for education and information programs.

Dr. Beverlee Myers was a remarkable individual, a scientist and administrator of tremendous vision but in addition, she also represented something very special in health policy: she was a beacon, a figure of strength where there were few people of sufficient courage to join her. Dr. Myers' death in December 1986 has been a loss to California's public health, scientific, and educational communities. Indeed for all Californians her death is particularly felt at this time in addressing the needs of the AIDS epidemic. We believe that Dr. Myers would certainly approve of and support this effort - to develop long term planning needs for AIDS services and for the prevention of transmission of the AIDS virus. And it is in this spirit and to the memory of this remarkable woman that we dedicate this planning effort.

CALIFORNIA'S WAR ON AIDS

EXECUTIVE SUMMARY

The Health Policy and Research Foundation, created in early 1986 at the request of Ken Kizer, M.D., M.P.H., Director of the California Department of Health Services, has been pleased to facilitate the development of "CALIFORNIA'S WAR ON AIDS".

It has been prepared with the advise of, and evaluation by, an Executive Committee comprised of 130 Federal, State, County, local, corporate, foundation, religious, and community based AIDS experts and Co-Chaired by five of our Country's most widely respected AIDS scientists: James Chin, M.D., M.P.H., California Department of Health Services; Donald Francis, M.D., D.Sc., Centers for Disease Control; Michael Gottlieb, M.D., University of California, Los Angeles; Alan McCutchan, M.D., University of California, San Diego; and Warren Winkelstein, M.D., M.P.H., University of California, Berkeley.

The process, which began in mid November 1986, involved the distilation and prioritization of the recommendations included in both the Surgeon General's Report on AIDS and the Institute of Medicine report Confronting AIDS. Consultants and advisors then developed program goals and objectives and, using detailed data from five sample California counties, extrapolated programs and costs statewide.

Attached to this summary you will find, a Treatment summary sheet based on the implementation of the necessary service components and anticipated treatment costs. Additionaly we have summarized Prevention objectives identified as necessary to prevent further spread of the HIV. What follows are 10 recommended immediate actions steps made by the Executive Committee Co-chairs.

Policy Recommendations

(1) The Legislature and Governor, setting aside partisan and political considerations, immediately call a "SUMMIT" meeting of all possible funding sources: Federal, State, County, local, corporate, foundations, religious, and community based organizations to take responsibility to develop the public-private partnership which will be necessary to collaboratively fund the "WAR ON AIDS". Only by bringing together all possible funding sources will we be able to launch the comprehensive, coordinated programs it will take to care for those already ill, intervene with those who are infected but not yet ill, and prevent those not yet infected from exposure.

(2) The Legislature and Governor, again setting aside partisan and political considerations, declare a state of emergency, setting aside normal budget limitations to enable them to fund California's share of the needs so as to avoid the imminent fiscal crisis further inaction will cause.

(3) Recognizing that this "WAR ON AIDS" is based on the recommendations of the Surgeon General's report and the Institute of Medicine report, the Legislature should pass and the Governor sign the legislative tool which mandates their implementation: Assemblyman Art Agnos' Assembly Bill 87.

(4) The California Health and Welfare Agency should contract with a non-governmental organization to continue and expand long term strategic planning exemplified by the "WAR ON AIDS" in order to anticipate opportunities to minimize the impact AIDS will have on Californians. Planning should focus on treatment quality control, data collection on cost of care, intervention to preclude illness, and prevention of further spread.

(5) The California Department of Insurance and Corporations should immediately work with the representatives of the Health Insurance industry to initiate "stop loss" and "risk" pools so as to preclude a private and employment based health insurance crisis here in California.

Fiscal Recommendations

We propose that the Legislature immediately augment the existing AIDS programs in the 1987/88 Budget and the Governor support them in order to initiate critical programs allowing us time to arrange the balance of funding by a collaboration between Federal, county, local, and private sources:

(1) Clinical drug trials: In the absence of intervention by antiviral drugs which preclude or delay progression from asymptomatic HIV infection to clinical opportunistic disease, the costs both in terms of suffering and treatment expense will be staggering. We recommend that the existing clinical drug trial consortia funded by the State of California be augmented by $2,000,000 and that an additional $1,000,000 be designated to create a system through the Alternative Test Site network to distribute expediantly any and all drugs felt to be safe and effective by the consortia, irrespective of having completed the Federal Food and Drug Administration licensing requirements. We propose that the consortia immediately independently analyse existing or completed trial data, or initiate wide spread drug trials into any antiviral or immunoenhancer agent for which there is rational scientific basis for testing. (Proposed augmentation: $3,000,000)

(2) Public health education and risk reduction programs: In the absence of a vaccine, education is our greatest tool. The vast majority of Californians are not yet exposed to the HIV. We propose that $2,000,000 be earmarked for the prevention of

spread among intravenous drug users; $1,000,000 each to augment existing preventive efforts among minority populations, sexually active heterosexuals, and homsexual/bisexual males. (Proposed augmentation: $5,000,000)

(3) Creating and expanding our ability to treat AIDS patients both humnanely and cost effectively: In order to avoid unecessary and expensive acute and sub-acute care we propose the expansion of existing skilled nursing and home health care pilot projects by $2,000,000, and creating residential hospice pilot projects for $1,000,000. (Proposed augmentation $3,000,000.)

(4) Initiate effective case management: Through the creation of Regional AIDS Treatment Centers we propose the coordination of effective services spanning the range of the continuum of care including acute, sub acute, skilled nursing, residential, hospice, home health, attendant care and outpatient services. (Proposed augmentation $6,000,000)

(5) Case monitoring and seroprevalence studies: In order to effectively plan to target prevention activities, evaluate their efficacy and anticipate treatment needs, we propose more rigorous case monitoring, seroprevalence studies and test linked counseling. (Proposed augmentation $3,000,000)

Careful reading and analysis of the report will demonstrate that these recommendations have been carefully developed, documented, and represent the minimum immediate action necessary.

Today we have the opportunity and the tools to minimize the impact this epidemic will have on our society. As public health experts we ask California citizens and elected officials to make the necessary policy, fund the necessary pilot projects and implement the necessary programs our research demonstrates are absolutely critical to containing this crisis.

Prevention Summary

Introduction

As California approaches a cumulative total of 8,000 cases of AIDS in the Spring of 1987 and looks at the prospect of 50,000 cases by the end of the decade, it is imperative that programs be undertaken to prevent further transmission of the HIV virus. Evidence indicates perhaps 1,000,000 Californians may fall into high risk categories and adequate public health measures including case monitoring, seroprevalence studies and HIV antibody test linked counseling as well as effective public health education measures need to be undertaken. The Prevention Summary is comprised of 2 sections: 1. Public Health Prevention; and 2. Public Health Educational/Behavioral Interventions:

1. Public Health Prevention

-> $7,800,000 is recommended to be spent at once to develop and expand epidemiological capacities including case reporting, seroprevalence studies of HIV, as well as to have appropriate personnel, including physicians, epidemiologists, public health behavioral scientists, health educators, evaluation specialists, lab personnel and support staff.

-> $13,200,000 is recommended to expand test linked counseling at anonymous test sites and to begin programs of confidential testing.

2. Public Health Education/Behavioral Intervention

-> Given the emphasis placed on public health education by the Institute of Medicine report, recommendations are made regarding the development and implementation of targeted interventions directed to 9 sub-populations and the general public. Funds for evaluation and assessment are also included.

IVDU = intravenous drug user

-> Among the high risk populations, the State's IVDUs are paricularly in need and approximately $13,000,000 in education risk reduction programs and methadone treatment funds are sought.

-> Approximately $10,700,000 is recommended for programs and interventions directed to homosexual and bisexual men.

-> Sexually active heterosexual populations and minority populations are in need of interventions. $11,725,000 is recommended for information dissemination, media programs and risk reduction activities.

-> Teenagers were felt to be a population in need of special interventions. The recommendation is for $3,050,000 in programs directed to adolescents.

-> Recent surveys among the state's health care providers indicate much education still needs to be undertaken with physicians, nurses, social service agency representatives, and other care providers, as well as first response providers. $1,550,000 is recommended.

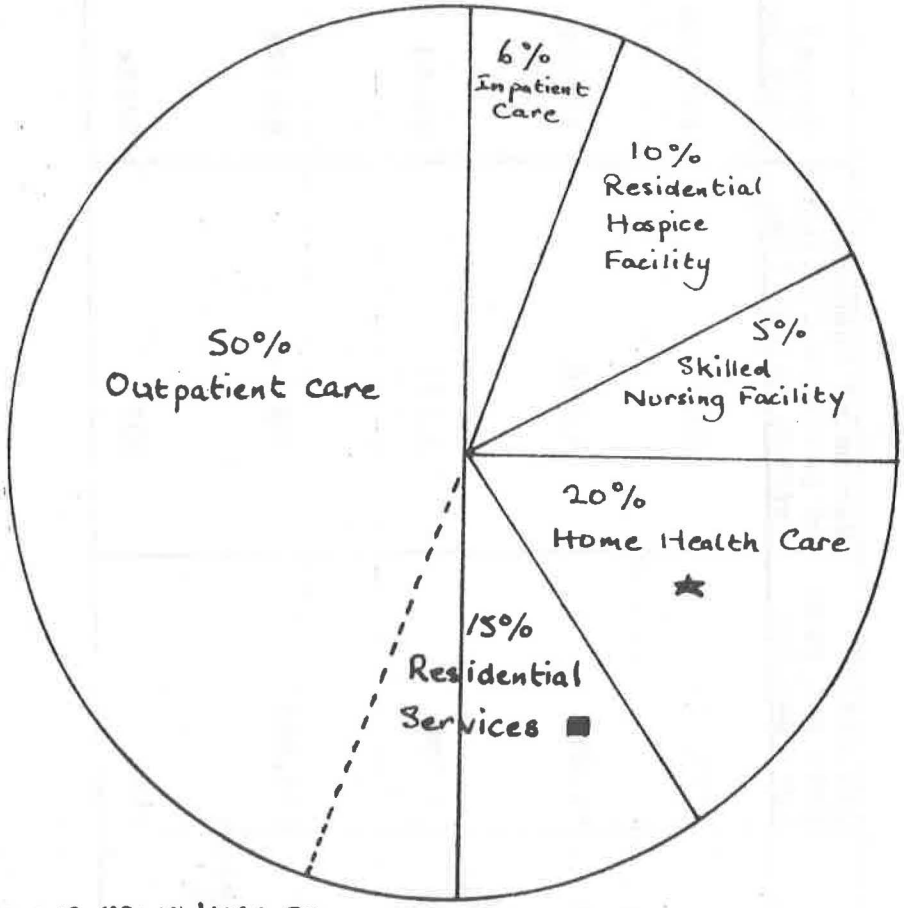
-> Prisons and prostitutes were also targeted for intervention, being two populations at increased risk. $1,950,000 in funding is recommended.

-> The general population of the state needs education about the disease. $19,350,000 is recommended. (approximately $.70 per Californian)

TOTAL PREVENTION BUDGET $82,875,000 or $3 per Californian

CALIFORNIAS WAR ON AIDS 1987-1991

Estimated Service Utilization Chart for H.I.V. infection stages III+IV



PATIENT CATEGORIES USING MORE THAN ONE SERVICE COMPONENT.

Casemanagement Services for 100% of patient population.

Emotional Support Services for 100% of patient population.

★ 5% Intermittent Nursing.
15% Attendant Care.
12% Home Support Services.
1% Critical Mental Health Care in the home.

■ 10% Shared and Referred housing.
5% Shanti-type housing.

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Estimate Service Utilization and Cost of Care for HIV infection in California in 1987 for 5370 living AIDS/Severe ARC patients

(A) Service Overview

Percentage of living patients in stages I - IV, HIV infection	Service Component	Estimated Cost per year per patient	Estimated numbers of patients utilizing service at one time	Annual cost for 1987	% of total budget
6% of HIV infected stages III & IV	Inpatient care	$319,375	322	$102.8m	55.5%
100% HIV stages III & IV	Case management	$1,000	5,370	$5.37m	3%
50% of HIV infected stages III & IV	Outpatient care for HIV symptomatic (stagesIII & IV)	$1,500	2,685	$4.03	2.2%
5% of stages III & IV	Residential services (Shanti model)	$12,000	268	$3.22m	1.5%
10% of HIV stages III & IV	Residential services Shared housing & referral	$500	537	$269k	.2%

Health Policy and Research Foundation
Estimate Service Utilization and Cost of Care
for HIV infection in California in 1987
for 5370 living AIDS/Severe ARC patients

(A) Service Overview (continued)

Percentage of living patients in stages I - IV, HIV infection	Service Component	Estimated Cost per year per patient	Estimated numbers of patients utilizing service at one time	Annual cost for 1987	% of total budget
10% of HIV stages III & IV	Residential Hospice Facility (Coming Home Model)	$51,100	537	$27.44m	15%
5% of HIV stages III & IV	Skilled Nursing Facility	$82,125	268	$22m	12%
1% of HIV stages III & IV	Critical Mental Home Services	$4160	54	$225k	.1%
5% of HIV stages III & IV	Home Health Skilled Nursing	$15,600	268	$4.18m	2.3%
15% of HIV stages III & IV	Attendant Care	$12,480	806	$10.1m	5%
12% of HIV stages III & IV	Home Support Services	$500	644	$322k	.2%
100% of Stages III & IV	Emotional Support Services	$1,000	5370	$5.37m	3%
				$185.326m	100%

Health Policy and Research Foundation
Estimated Service Utilization and Cost of Care
for HIV Infection in California in 1987

(B) Anticipated Outpatient and Medication Costs

Percentage of Living Patients Stages 1-4	Service Component	Estimated Cost per year per patient	Estimated numbers of patients utilizing service	Annual Cost
100% of HIV infected Stages I & II	Outpatient care	$600	300k	$180m
100% of HIV infected Stages I & II	Outpatient care (Medication/drug intervention)	$3,000	300k	$900m
75% of HIV stages III & IV	Medication and Drug Intervention	$9,000	4,028	$36.25m
			Annual Total	$1.116b

SECTION I

PREVENTION

prepared by

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

GOALS AND OBJECTIVES FOR THE PREVENTION OF AIDS IN CALIFORNIA

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.

I. Public Health Prevention

A primary public health function 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 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 groups, 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 public health prevention have been identified as follows:

A. Case Monitoring

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 monitoring 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.

B. Serologic Monitoring

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

1. Perform anonymous or confidential serologic testing 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

C. Public Health Summary Reporting

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:

-> Monthly tabulation of all data sources
-> 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.

D. Test Linked Counseling

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 75,706 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 persons 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.

Capabilities of ATS sites in the state will be expanded so that:

1. Anyone in California seeking to be tested for HIV should be able to do so; all counties will offer annonymous testing programs for HIV on at least a sliding scale fee if not for free.

2. Increase capacity at centers to be able to test 50,000 -100,000 individuals.
3. All those seeking to be tested anonymously, should be able to be tested within 10 days of their request.
4. Anonymous testing will be offered in:

-> STD clinics
-> family planning clinics
-> methadone treatment centers

5. Anyone in California seeking or obtaining HIV testing should receive appropriate pre and post test counseling.
6. Mandatory testing of individuals should not be allowed as a prerequisite for entrance into drug treatment, or for incarceration or any other purpose.

E. Program Development and Coordination

Program development and coordination are crucial to addressing the prevention needs of the epidemic. Inadequate support can result in chaos and at the very least in poor utilization of scarce resources and personnel. New positions and job descriptions will need to be developed as current regulations and job specifications do not always meet needs. When necessary such job classifications should be expedited.

1. All counties with more than 10 cases of AIDS will establish an AIDS Program Office and hire appropriate personnel.

   a. Those counties with over 100 cases should hire a physician or Ph.D. epidemiologist 100% time to oversee program.
   b. Counties with more than 10 cases should designate physician or epidemiologist at least 50% time.
   c. Counties should expand laboratory, biostatistical and clerical support as needed.
   d. New positions at county and state levels will need to be created and new job descriptions and titles developed. (e.g. positions in public health behavioral science and evaluation, positions combining administration and other public health disciplines.

2. All county health departments should develop liaisons with neighboring counties and develop capacities for regional coordination and planning.

F. Other

1. 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.

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.

Education continues to be the primary modality for preventing further spread of HIV. 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 continue to be 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 her infant child. While there has been almost universal acknowledgment of the necessity of education for AIDS and some kind of outreach to those who engage in risk-taking behavior.

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 these areas needs to be utilized.

Targeted Populations

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

Homosexual and bisexual males who engage in unprotected sexual activity 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 unprotected sex, still many homosexual and bisexual males remain at risk. These individuals 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 unprotected 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. Effective skill building (including counseling programs) need to be developed and implemented.

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.
   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 Shanti 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. Counseling and psychological support for behavior change need to be incorporated as needed.

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

6. Develop two behavioral 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 (IVDUs)

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. In addition to utilizing 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 3 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. Sexually Active Heterosexual Populations

Sexually active heterosexuals must receive targeted information regarding risk of AIDS. Persons attending family planning, prenatal and STD clinics need to be informed regarding the disease and testing on a confidential basis must be made available; 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 protective 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 should be alert to prevention opportunities. Teenagers and college students should be targeted for special AIDS information programs.

Objectives

1. Every individual attending a prenatal or family planning clinic will receive AIDS risk reduction education and counseling. Individual assessment will be made and referral for HIV testing if indicated and post-test counseling.

2. A statewide education and media campaign will be directed to heterosexuals regarding AIDS; part of this campaign would be a special AIDS Awareness month.

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. An AIDS Awareness Campaign will be directed to college and university students.

6. Individuals testing HIV positive will be asked to voluntarily notify their partners to follow-up.

D. Minority Populations

Both Black and Hispanic populations are at some increased 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. Pilot prevention/resource and centers will be established to serve as clearinghouses for information; individual assessment for AIDS risk can be made and referral as indicated for HIV testing and counseling. 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.

5. Develop a behavioral science/health education resource centers with AIDS risk reduction and health promotion activities as foci, one oriented to black community, one to the Hispanic community.

6. There should be evaluation and assessment of these community based programs.

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 and teen pregnency programs 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 empaphis 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; inservice should be undertaken with personnel who run these shelters.

5. All personnel of the California Youth Authority will receive inservice regarding AIDS. All individuals held in CYA facilities will receieve AIDS risk resduction education.

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.

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 in jail or prison will receive at least 10 minutes education about AIDS as part of being processed.
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 currently exist among (female) prostitutes; increases can be expected. Special efforts need to be undertaken to reach these individuals, direct them to appropriate clinics and screening facilities and educate them about protective 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 protective 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 protective 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 protective sex should be contiued.

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 campaigned 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. A Statewide telephone survey should be undertaken to monitor behavior changes and attitudes and effectiveness of the campaign.

5. The homeless of the State (400,000+ est.) are also at risk for HIV infection. An outreach program will be developed to target them.

6. All statewide business associations and local associations including Chambers of Commerce should develop AIDS briefings and programs such as AIDS in the workplace.

GOALS	CURRENT PROGRAMS	PROJECTED COST ESTIMATES FIRST YEAR
I. Public Health Prevention		
A. Case Monitoring		
1. Each county will develop an assessment and 4 year master plan for implementation of prevention programs including hiring of new personnel (i.e. public health nurses, epidemiologists, lab personnel, public health behavioral scientists, evaluation specialists.)	At least 5 counties have undertaken such needs assessments, particulary those hardest hit.	$250,000
2. Continue existing AIDS surveillance activities	All counties have at least passive surveillance systems; funding varies from county to county.	$1,000,000 - $2,500,000 depending on caseload. For each additional 250 cases add 1 FTE.
3. Expand case monitoring through implemenation of active surveillance techniques, use of sentinel physicians, medical and discharge review.	Only a very few counties presently have such active case monitoring.	
4. All cases of AIDS to be reported within 30 days of diagnosis	No program with this goal	
a. Begin to develop tracking system for other HIV categories	Orange county	
5. Closely monitor disease rates in diseases such as gonorrhea, syphlis, hepatitis B, T.B.	Only 2-3 counties currently monitor such rates.	$550,000

GOALS	CURRENT PROGRAMS	PROJECTED COST ESTIMATES FIRST YEAR
B. Serologic Monitoring		
1. Perform annonymous or confidential serologic testing for HIV at appropriate intervals on samples of: a. STD clinic patients b. Family planning patients c. Pre-natal clinic, parents d. pre-marital tests e. methadone clinic population	DHS program in 22 counties just getting underway.	$2,500,000 per year (25,000 samples at $100 per sample)
C. Public Health Summary Reporting	Most larger counties summarize AIDS case data only.	make monthly reports more systematic and detailed. $300,000 ($5,000 per county on average.)
1. Perform monthly a. all data sources. b. monthly reviews of programs in progress including: -> delays at ATS sites -> AIDS case reporting families -> education programs -> confidential tests summaries -> press reports		
D. Test Linked Counselling	Currently there are 54 ATS sites, 31 Jurisdictions.	$2,200,000 (50,000 tests)
1. Expand capabilities of ATS sites so that: a. each county has such a site b. increase by at least 100% capacity of current sites so that c. all those seeking testing can do so within 10 days of the request.		$4,400,000 (100,000 tests)

GOALS	CURRENT PROGRAMS	PROJECTED COST ESTIMATES
2. All counties will offer confidential testing programs in: a. STD clinics b. family planning clinics c. methadone offices d. physician offices	Very few counties offer confidential testing programs.	$8,800,000 (200,000 tests) $4,400,400 (100,000 tests)
E. Program Development/Coordination		Counties should develop capabilities. $2,000,000 to develop these programs. a. as the AIDS caseload increases FTE's will need to be added to existing programs (including physicians).
1. All counties with more than 10 cases of AIDS should establish an AIDS program office and hire appropriate personnel. a. Counties with more than 100 cases should hire M.D. or Ph.D. Epidemiologists to direct programs. Expansion of other programs.	Over 20 counties have such an office.	
2. All county health departments should develop liaisons with neighboring public health officials and health departments in their regions and meet on at least a quarterly basis.	Some county health departments currently have regional meetings (e.g. Bay Area Counties).	All counties, particularly smaller ones should develop regional working groups.
F. Other		
All counties should develop AIDS policies with regard to schools. As a general policy children with AIDS should be admitted to primary or secondary school.	Most counties have adopted AIDS policies regarding schools.	Programs should be undertaken with school boards and inservice programs developed for school personnel with cooperation of Department of Education.

Educational/Behavioral Intervention

Categories

Goals	Estimated Costs to Implement (at state level)
A. Homosexual Males	
1. Information dissemination/media campaign	$1,500,000
2. Expand "Stop AIDS" programs (100,000 males at $30)	3,000,000
3. Expand skill development programs such as SHEP (50,000 at $30.00)	1,500,000
4. Pilot programs to reach highest risk	1,500,000
5. Outreach to rural areas	500,000
6. 2 behavioral science/health education resource centers (health education laboratories)	500,000
7. Evaluation programs	400,000
8. Minority outreach	1,000,000
9. 2 pilot prevention centers (including HIV ab testing, T-cell serologics, counseling services)	800,000
	$10,700,000
B. IV Drug Users	
1. Street outreach	$3,000,000
2. Media campaign	2,000,000
3. Increase methadone treatment slots, detoxification slots, other treatment programs by 50%	6,500,000
4. Inservice for professionals in alcohol programs	550,000
5. Inservice for professionals in drug abuse progessionals	550,000
6. Establishment of IVDU intervention resource centers	250,000
7. Evaluation/assessment	400,000
	$13,250,000
C. Sexually Active Heterosexual Populations	
1. Each individual attending a family clinic	$1,500,000
2. Individuals attending STD clinics	2,000,000
3. Assessment and evaluation of staff and patient knowledge; health promotion recommendations.	200,000
4. Statewide education and media campaign directed to sexually active hetersosexuals	1,500,000
5. Outreach to sexually active heterosexuals and college students	1,000,000
6. Voluntary sexual contact referral	275,000
	$6,475,000

Educational/Behavioral Intervention

Categories

Goals	Estimated Costs to Implement
C. Minority Populations	
1. Information dissemination/media	$1,500,000
2. Innovative neighborhood/community outreach programs - including AIDS outreach "storefront" risk reduction centers	1,500,000
3. 2 pilot prevention/resource centers HIV ab testing, counseling services	800,000
4. Health care providers/clinics - inservice	550,000
5. 2 behavioral science/health education centers	500,000
6. Evaluation/assessment	100,000
	$5,250,000
E. Teenagers	
1. Every teen clinic will develop an AIDS information program	$ 250,000
2. Every school nurse, social worker will receive inservice	550,000
3. A teen/AIDS information campaign will be developed	1,000,000
4. A street outreach will be developed to reach homeless and street youths	750,000
5. California Youth Authority	500,000
	$3,050,000
F. Prison Populations	
1. Education inservice about AIDS in state prisons and county jails	$ 550,000
2. Every individual held in facility will receive information and education on AIDS	500,000
3. Every jail and prison facility will have information on AIDS risk reduction	100,000
	$1,150,000
G. Prostitutes	
1. Innovative interventions through STD and AIDS outreach workers	$ 250,000
2. AIDS Awareness campaign for prostitutes in each county	550,000
	$ 800,000
H. Hemophiliacs	$ 300,000

Educational/Behavioral Intervention

Categories

Goals	Estimated Costs to Implement
I. Health Care Professionals	
1. Statewide training program for health care providers	$1,000,000
2. Information program for police and first response providers	550,000
	$1,550,000
J. General Population	
1. Mailing to every family (short pamphlet)	6,000,000
2. Media campaign (1 year)	10,500,000
3. Hotlines- increase as needed	750,000
4. Statewide telephone survey to monitor/assess campaign (2X)	600,000
5. Homeless outreach programs - inservice to homeless shelter personnel	500,000
6. AIDS in the workplace	1,000,000
	$19,350,000

APPENDIX I

Goals and Objectives for the Prevention of AIDS in California

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

-> 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.

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 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 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, 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.

SECTION II

TREATMENT

prepared by

Rev. Albert Ogle

Treatment Summary

Introduction

As Californians prioritize the Institute of Medicine report Confronting AIDS and the Surgeon General's report, it will be necessary to review, adapt and expand our AIDS related health care in metropolitan and rural communities. Although California is spending more than ever on AIDS related programs, the anticipated increase in HIV infection over the next 5 years and the intensity and complexity of services required by patients, demands careful long term planning to establish cost effective and efficient models of community based care. The Institute of Medicine report says;

"Based on experience to date, the committee believes that if the care of these patients is to be both comprehensive and cost effective, it must be conducted as much as possible in the community, with hospitalization only when necessary. The various requirements for the care of patients with asymptomatic HIV infection, ARC or AIDS (i.e. community based, outpatient care, hospitalization) should be carefully coordinated."

The Process

This plan is the first comprehensive step towards this goal for California where the AIDS epidemic is out of control. We have reviewed the existing AIDS-related health care system in 5 sample counties; San Fransisco, Los Angeles, Santa Cruz, Orange and El Dorado counties. We have consulted with our Evaluation Committee of 130 leading AIDS related professionals in the State, and have been assisted by public health experts in other states and others with national perspectives on the epidemic. We have developed a suggested matrix of necessary program components coordinated by regional AIDS Treatment Centers which could be applied to any region in California. These programs are designed to minimize inpatient care and maximize our limited resources. The plan also includes a proposed system for statewide coordination and planning through an AIDS Commission and Regional AIDS Councils with technical review and monitoring services from support staff.

Estimating Service Utilization and Cost 1987 - 1991

The final part of the plan is an estimated service utilization projection over the next five years with cost estimates based on existing programs. It is clear from this report we are spending our limited resources on sometimes inappropriate and costly services for people with AIDS/ARC. There are still many gaps in the health care continuum which need to be filled if we are going to humanely and cost effectively plan for care over the next 5 years. From a health planning perspective, with AIDS, we can fairly accurately project numbers of people requiring certain types of service over the next 5 years. Patterns of service utilization are beginning to emerge and will be helpful in developing comprehensive treatment in metropolitan and rural communities.

Project Goals

Goal 1 - Establish the State Commission on AIDS to coordinate and oversee the development of prevention, education and treatment strategies and programs for HIV infection in California.

Goal 2 - Contract with a independent organization specializing in long term strategic planning in California to review, evaluate and make recommendations concerning the efficiency and effectiveness of AIDS related prevention, education, treatment and management services for HIV infection in California.

Goal 3 - Implement policy and program recommendations outlined in this report by:

(a) Establishing State AIDS Commission.
(b) Establishing Regional AIDS Councils
(c) Establishing Regional AIDS Treatment Centers and an equitable system to enter into contracts with them.
(d) Initiating and implementing legislative policy program reforms outlined in Goal 4.

Goal 4 - Implement legislative and policy reforms to improve AIDS related services. This will be achieved by;

(a) Increasing Medi-Cal reimbursement rate for AIDS related services.
(b) Reviewing and reforming residential and health care facility regulations and the licensing process.
(c) Reviewing and reforming existing health care legislation and programs to include people with HIV infection. (i.e. the Family Survival Project and the Genetically Handicapped Persons Program, Homemaker Services, Respite Care, etc.)
(d) Reviewing and reforming AIDS related prevention and health care delivery to juveniles and adults in detention in California.
(e) Developing equitable ways to finance the cost of care for HIV infection through a state based insurance risk pool for the uninsured and those with catastrophic illness.
(f) Instigating immediate data collection and review on insurance eligibility, cost of care and issues associated with income maintenance for people with AIDS/ARC and make appropriate reforms and program priorities to meet the social and welfare needs of patients

Goal 5 - To provide care for estimated numbers of patients in California in a manner which is medically appropriate, psycho-socially supportive and culturally sensitive as well as being cost effective. This will be achieved by:

(1) Estimating the numbers of patients who will utilize certain services at any one time.
(2) Estimating the cost of care in each service component.
(3) Establishing a health care matrix and estimated percentage of patients who will utilize each service component .

Goal 6 - To develop a model of comprehensive care to patients with HIV infection, which could be used in any region in California, by developing a service matrix and case management system through designated AIDS Treatment Centers. These will have the following nine service components:

(1) Outpatient care for asymptomatic HIV infected
(2) Outpatient care for symptomatic HIV infected
(3) Inpatient care
(4) Case management services
(5) Residential services
(6) Sub-acute care including skilled nursing, and residential hospice facilities.
(7) Home health, nursing, attendant and respite care
(8) Volunteer services with professional supervision
(9) Emotional support services

THE TREATMENT PLAN FOR HIV INFECTION IN CALIFORNIA 1987 - 1991

Introduction

In the past 12 months, the Surgeon General's report and the Institute of Medicine's report have highlighted the national impact of AIDS on the American health care system. The implications of their recommendations requires a complex system of cost effective community based services to complement and minimize hospitalization. The various components needed in the care of patients with a asymptomatic infection, ARC or AIDS (i.e. community based care, outpatient care, hospitalization) should be carefully coordinated nationally, regionally, and locally. This challenge is now facing California. California has 7,742 cases of AIDS (March 31, 1987) and anticipates 50,000 cumulative cases by 1991, 17,000 of whom will require health care in 1991 alone (CDC report 12/86). These figures are deemed to be low projections by prominent local researchers, but will be used as the minimum anticipated increased numbers requiring treatment. This report suggests ways in which California can organize, prioritize, plan for prevention, education and treatment, and how to best gather data on cost, type and effectiveness of care, while developing those service components which appear to be most suitable and cost effective. The report will suggest ways in which existing policies and legislation could be reformed to include these services for patients with HIV infection.

We assume the private sector will be actively involved in state and regional planning efforts to prevent the spread of the disease, educate the community and care for the victims of the disease. This crisis has created new alliances and networks between health professionals, the academic and business communities, religious, ethnic and other diverse groups. It is imperative for us to continue to develop public/private AIDS initiatives, particularly in California. The Robert Wood Johnson Foundation is the leading AIDS related philanthropic foundation in the country with it's 4 year $21 million Health Policy Program for AIDS. Four metropolitan areas in California applied for funding comprehensive care systems for AIDS in 1986. The failure to fund these programs has created a vacuum in California which has not yet been filled by either the public or private sectors. This report outlines what that vacuum is, and how we can begin to fill it.

1. Prioritizing the Institute of Medicine's Report for California

The overall goal of prioritizing the Institute of Medicine's recommendations for California is to establish a cost effective and efficient continuum of health care for people with HIV infection, applicable to metropolitan and other areas in the state. This will be achieved through the following goals:

(1) Establishing a State Commission on AIDS
(2) Appointing a review organization for California
(3) Implementing policy and program recommendations outlined in this report.
(4) Implementing legislative and policy reforms to improve services outlined in this report.
(5) Providing care for estimated number of patients in California in a manner which is medically appropriate, psycho-socially supportive and culturally sensitive as well as being culturally sensitive.
(6) Developing a model of comprehensive care to patients with HIV infection, which could be used in any region in California by developing a service matrix and case management system through designated Regional AIDS Treatment Centers.

2. The Treatment Planning Process

The overall priorities for California were based upon the counsel of 130 experts in public health, the public/private sector, religious, academic and care provider communities who monitored the development of an initial statewide plan for HIV infection. Recognizing the limitations of time and resources, this Evaluation Committee suggested we look at the health care continuum in 5 sample counties. San Francisco County which has developed an extensive 2 year plan; Los Angeles County which developed an extensive community wide needs assessment and preliminary plan in 1986, and will develop a plan for the County Health Department in October 1987; El Dorado County with reference to its relationship with neighboring counties, particularly Sacramento; Santa Cruz County and its relationship to the Bay Area counties, particularly the San Jose area; Orange County and its relationship to Los Angeles and other surrounding counties.

The purpose of the site visits was not only to investigate the numbers of patients, levels of care and methods of coordination and case management, but to see if some of the existing San Francisco models of care (i.e. Shanti type shelters or home health care, could be effective in smaller counties).

In developing a statewide system of AIDS treatment, we thought it important to suggest basic program components which could be duplicated and expanded in rural and metropolitan areas, suitable to large county hospitals and smaller physician-based outpatient clinics.

The case management model which was developed is based on the existing Blue Shield model and the Home Health Care Pilot Project, centralized at AIDS Project Los Angeles. The assumption underlying the case management model is the existence of a

series of outpatient and community based services and programs where AIDS/ARC patients can be maintainted at home or home like settings for as long as possible. Without these necessary underpinning services, the overall goal fo the statewide plan of providing community base cost effective care will not be achieved. Six basic goals are outlined in the report which follows.

THE TREATMENT PLAN FOR HIV INFECTION IN CALIFORNIA 1987-1991

Goal 1 - Establishing the State Commission on AIDS to coordinate and oversee the development of prevention, education and treatment strategies and programs for HIV infection in California.

A. The State Commission on AIDS and Appropriate Staff

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 and augmenting existing programs. It is important to appoint representatives of various governmental departments, AIDS service providers, academic institutions, religious organizations, public health experts, health planners and insurance and business interests, with appropriately skilled staff. The Commission's charge would be to address the personal, economic, political and social impact of AIDS for California, particularly over the next five years with assistance and input from designated Regional AIDS Councils.

Staff would 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. They would ensure that as problems in the community are identified, staff would assist providers in developing solutions as part of their overall activities. They 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 would attempt 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. Staff would be important facilitators in this necessary process to establish long-term AIDS planning. Staff would be particularly responsible for:

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.

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.

Goal 2 - Appoint a review organization for long term planning in California to review, evaluate and make recommendations concerning the efficiency and effectiveness of AIDS related prevention, education treatment and management services for HIV infection in California.

The Commission may also appoint a review organization to be concerned with monitoring the activities of the proposed hospital based 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 necessary for AIDS planning:

   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.

Goal 3 - Implement policy and program recommendations outlined in this report. by;

a. Establishing the State AIDS Commission and appropriate staff.

b. Establishing Regional AIDS Councils.

c. Establishing Regional AIDS Treatment Centers and an equitable system to enter into contracts with them.

d. Initiating and implementing legislative policy and program reforms outlined in goal 4.

These steps will need to be undertaken immediately:

1. Necessary legislative approval of the structure and funding required to establish the State Commission on AIDS and appoint appropriate staff.

2. The Office of AIDS develops a proposed regional inter-county structure which allows for the existing AIDS networks and service delivery networks to appoint local Regional AIDS Councils who will be advisory to the AIDS Commission, the Office of AIDS, and Local Boards of Supervisors. Technical assistance to the Councils should be provided by the staff of the Aids Commission. Regional AIDS Councils should be concerned with long range planning, resource development, problem solving and management 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 contracting with Regional AIDS Centers. It may be appropriate for the State to request one comprehensive agreed plan from an applicant in a particular region to improve collaboration at local levels (similar to the Robert Wood Johnson AIDS Health Program application process). Regions who sent more than one application were requested to work together on improving proposals and collaborating with competing applicants. The 4 applicants who submitted proposals in California did so with the full support of their service provider colleagues. This would encourage greater collaboration between hospitals wishing to establish State contracts as AIDS Treatment Centers, and their service provides colleagues, some of whom will be subcontracting services (see appendix 3). It will also

minimize the competitive process which often wastes valuable resources and increases service duplication at local levels. Building local consortiums should be an important function for the staff of The State AIDS Commission.

Goal 4 - Implement legislative and policy reforms to improve AIDS related services. This will be achieved by;

a. Increasing Medi-Cal reimbursement rate for AIDS related services.

b. Reviewing and reforming residential and health care facility regulations and the licensing process.

c. Reviewing and reforming exisiting health care legislation and programs to include people with HIV infection. (i.e. the Family Survival Project and the Genetically Handicapped Persons Program, Homemaker Services, Respite Care, etc.)

d. Reviewing and reforming AIDS related prevention and health care delivery to juveniles and adults in detention in California.

e. Developing equitable ways to finance the cost of care for HIV infection through a state based insurance risk pool for the uninsured and those with catastrophic illness.

f. Instigating immediate data collection and review on insurance eligibility, cost of care, and issues associated with income maintenance for people with AIDS/ARC and make appropriate reforms and program priorities to meet the social and welfare needs of patients

Examples of how existing legislation and policies are affecting AIDS health care.

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

A. 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 cost effectively meet client needs.

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 reimbursement rates. The extra expenses would be needed to cover staff education, infection control, labor, mental health, case management services, and increased liability and other insurance costs.

A survey in 1986 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 had 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 which was significantly less costly than admitting them to hospital.

B. <u>The need for review and reform of the licensing criteria and process for residential and health care facilities</u>

A Case Study - "Coming Home"

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 hospice setting for 15 terminally-ill AIDS patients. The project was a remarkable community success with public funding for the project marked dollar for dollar by the enthusiasm and altruism of the local community. Two years later, the facility has just been opened, and recently attracted major media attention 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 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 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 Services had 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, but there is no licening category which adequately addresses their work.

A Possible Solution

A joint committee composed of representatives of the Department of Social Services, Department of Health, hospice organizations, and the Shanti Foundation could help to develop new policies on all levels of residential care where intermittent nursing care is needed. This is of major importance to AIDS related health care and deserves immediate attention.

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 under "Residential Hospice Facilities".

Another issue which would need to be examined simultaneously is the assurance that existing 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 regulations 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 could also be charged with assisting community agencies wishing to establish Shanti-based housing models. One social service administrator willing to somehow 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 and regulation 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 these services.

(C). The need to reform existing health related programs and legislation to include and be utilized by people with HIV infection.

Several important existing programs could easily include people with AIDS/ARC 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 infection could be listed with the list of brain damage factors. Further funding and resources could 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, pyscho-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.

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 Policy and Legislative 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 needs to include unmarried men's 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. There is need to 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.

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, (symptomatic)..

i. As we develop community based health care, particularly home health, we will need to establish respite and care for significant others, family members and principal care givers.

Recommendations on Policy Issues

1. The goals of the comprehensive Treatment Plan are agreed upon by an appointed State AIDS Commission with a budget approved to meet the program goals.

2. Appropriate staff will be appointed by the Commission.

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 care facilities.

5. Staff of the AIDS Commision should provide technical assistance to communities developing home health, adult residential facilities, residential hospices and independent residences for people with HIV infection 3 and 4.

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

7. Staff 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:

    a. Income maintenance for persons with AIDS/ARC

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

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

    d. The effectiveness of existing administrative, advisory, and informational systems which support the AIDS service continuum throughout the State with recommendations to improve these systems.

12. Policies regarding patient confidentiality and control over care and all care providers will be established. To accomplish this goal, policies will need to be developed to obtained consent from the patient for each care provider regarding HIV information on each patient. Additionally rules regarding strict confidentiality of HIV information on each patient will need to be set forth with clearly state consequences for their violations.

13. Legislation be enacted which will provide special education and services for children with AIDS and their

families. This may require additions to Public Law 94142 and local state law for education for the handicapped.

Goal 5 - To provide care for estimated numbers of patients in California in a manner which is medically appropriate, psycho-socially supportive and culturally sensitive as well as being cost effective. The will be achieved by:

1. Estimating the number of patients who will utilize certain services at any one time.

2. Estimating the cost of care in each service component.

3. Establishing an accessible health care matrix to give appropriate care to an estimated percentage of patients who will utilize each service component.

A. Introduction to the Estimated Service Utilization Chart and Projected Costs

The projected numbers of AIDS cases used in these projections are based on the Statistics and Data Management Branch of the AIDS Program or the Center for Disease Control. They were extrapolated for California by Dr. W. Meade-Morgan in December 1986, representing 23% of the national total. (see Appendix 5) These figures were used by the California Legislative Analyst's Report in March 1987, looking at the magnitude and cost of the AIDS/ARC epidemic over the next 5 yeaars. The Department of Health Services has estimated that the official state counts of reported AIDS cases may understate the number of AIDS cases by 17-25 percent. For example, in November 1986, San Francisco County reported it had 2654 cumulative cases while DHS estimated 2370 cases.

Other researchers project higher numbers than those included in this document - some by 30-50% (Goedert 1986, Johnson 1986, Scitovsky/Rice 1987, Pascal, forthcoming 1987). There is agreement that the data on service utilization and cost of care is still in its infancy and our projections can only be provisional. Ann Scitovsky will be completing her "Total Cost of AIDS Care Study" in San Francisco and Los Angeles later this year. The estimated cost of inpatient, outpatient, hospice, home health, residential services is based on existing California programs. More detailed research on home health care for AIDS/ARC patients will be available from the Department of Health Services in June 1987. Preliminary data from this pilot project involving 130 patients with symptomatic HIV infection is showing 55% are employed full

time, 15% working part time, and 25-30% require minimal care at home. 10% of this sample are hospitalized at any one time This is higher than San Francisco's 6% where more sub-acute and AIDS related community services are available.

B. Patients estimated needs and services

The Kaiser Report (1986) estimated that 50% of diagnosed AIDS patients were fairly mobile, self sufficient and needing outpatient care only. This was based on data from San Francisco. The most recent data from San Francisco shows that 6% of AIDS patients at any one time are inpatients in one of the San Francisco hospitals. The others are being cared for in the hospices, home health care, residential programs and in outpatient clinics. A recent estimate of people with AIDS who are in need of either residential services or housing subsides in Los Angeles will be helpful projecting anticipated services. Aid for AIDS in Los Angeles provides monthly housing subsidies to 6% of the AIDS population which is often the difference between having a home and being homeless. We are estimating 5% of people with AIDS/severe ARC will require Shanti-type residential care throughout the state and 10% will need assistance with finding low income housing through a referral/shared housing program (based on a model in San Jose). Special programs will need to be created for women with AIDS, women and children with AIDS who need residential care and children with AIDS who will need residential and day care services - perhaps at the same facility.

The Home Health Care Pilot Project shows 20% of the patients utilize home health and attendant care. This should be supported with respite care for live-in caregivers, either through the existing homemakers service, or giving emotional and practical support through a professionally supervised 'buddy' system providing emotional support for the duration of someones illness. The importance of volunteer participation in these programs demands greater professionalism and supervision of existing and anticipated services.

Five percent (5%) of patients treated at home will need intermittent skilled nursing, 15% attendant care, and 1% will need professional psychotherapeutic monitoring at home because of organic brain syndrome or suicidal ideation.

We estimate 10% of the target population will need a hospice facility in which to die. The 'Coming Home' model in San Francisco provides care for 15 terminally ill patients at a cost of $51,100 per year each. The hospice model is more suitable for patients who have no-one to care for them at home.

An estimate of 5% of AIDS/severe ARC patients will utilize skilled nursing facilities. These should accomodate the special needs of patients suffering from AIDS related diseases including dementia or drug related problems which require specialized facilities and specialized staffing. Some of the estimated costs will need to be allocated towards drug rehabilitation programs and facilities providing services to people with dementia. In the Home Health Care Pilot Project, 65% of patients showed organic involvement. 5% had suicidal ideation.

C. Estimated Service Utilization Chart for Symptomatic HIV Infection (Stage 3 and 4)

We will use a recent Centers for Disease Control heirarchial definition for the populations who will be expected to utilize the programs outlined in the plan.

The stages are:

I. Acute HIV infection

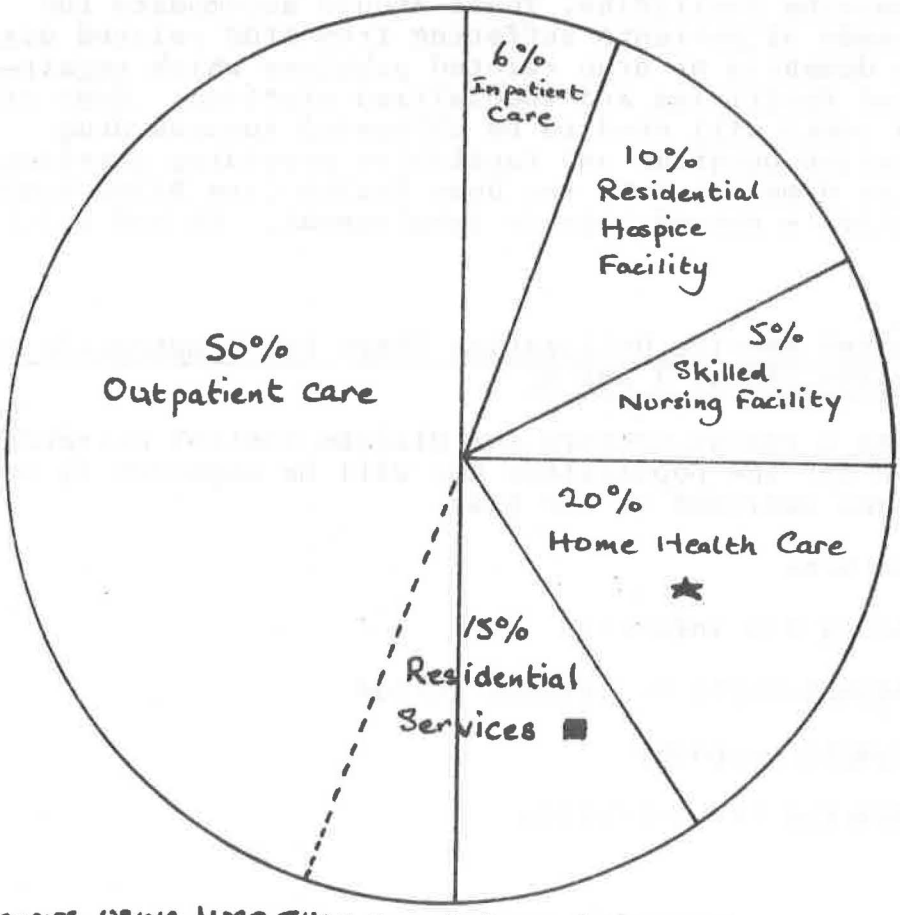
II. Asymptomatic or latency period

III. Lymphadenopathy

IV. Symptomatic infection

CALIFORNIAS WAR ON AIDS 1987-1991

Estimated Service Utilization Chart for H.I.V. infection stages III+IV



PATIENT CATEGORIES USING MORE THAN ONE SERVICE COMPONENT.

Casemanagement Services for 100% of patient population.

Emotional Support Services for 100% of patient population.

★ 5% Intermittent Nursing.
15% Attendant Care.
12% Home Support Services.
1% Critical Mental Health Care in the home.

■ 10% Shared and Referred housing.
5% Shanti-type housing.

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The Health Policy and Research Foundation
Estimated Service Utilization and Cost of Care for HIV Infection in California /1987-1991
(1) Patients Requiring Treatment

Overview	1987 Estimated Patients	1988 Estimated Patients	1989 Estimated Patients	1990 Estimated Patients	1991 Estimated Patients
CDC Defined AIDS					
Number alive from 1981-31st December 1986	3182				
Number of new cases during year minus fatalities	1,700	2,100	2,500	2,900	3,300
Total alive at end of year	4,882	6,982	9,482	12,382	15,682
Estimated Severe ARC 10 AIDS:Severe ARC	488	698	949	1,238	1,568
Estimated ARC (10 ARC / 1 AIDS)	48,820	69,820	94,820	123,820	156,820
Total No. of patients needing care in stages III & IV	5,370	7,680	10,431	13,620	17,250

Health Policy and Research Foundation
Estimated Service Utilization and Cost of Care for HIV Infection in California/1987-1991
(2) Services, Patients and Cost

Program Component	1987 Patients	Est. Cost	1988 Patients	Est. Cost	1989 Patients	Est. Cost	1990 Patients	Est. Costs	1991 Patients	Est. Costs
1. Inpatient Care for HIV infection stages III & IV										
6% of cumulative CDC Defined AIDS in hospital at any one time	293		419		569		743		941	
.06% of Cumulative Severe ARC	29		42		57		74		94	
Average cost of inpatient care using Scitovsky & Rice 1986 data = $875 per day x 365 days $319,375	322	$102.8m	461	$147.2m	626	$200m	817	$260m	1035	$330m
2. Case management for HIV infected stages III & IV										
($150,00 Case management unit = $1,000 per patient) 100% of AIDS severe ARC needing this service	5,370	$5.37m	7,680	$7.68m	10,431	$10.43m	13,620	$13.62m	17,250	$17.25m

(2) Services, Patients, and Cost (continued)

Program Component	1987 Patients	1987 Est. Cost	1988 Patients	1988 Est. Cost	1989 Patients	1989 Est. Cost	1990 Patients	1990 Est. Costs	1991 Patients	1991 Est. Costs
3. Outpatient Care	300,000		325,000		350,000		360,000		365,000	
(a) Stages I & II Estimating 3 visits per year @ $200 per visit		$180m		$195m		$210m		$216m		$219m
(b) Stages III & IV Estimating 50% of Total AIDS/Severe ARC will be self sufficient and will only need outpatient care 6 visits per year @ $1500 per year (New York AIDS Center estimate)	2,685	$4.03m	3,840	$5.76m	5,216	$7.82m	6,810	$10.22m	8,625	$12.93m
(c) Medication/drugs @ $3,000 per patient	300,000	$900m	325,000	$975m	350,000	$1.05b	360,000	$1.08b	365,000	$1.095b
4. Residential Services										
(a) 5% of AIDS/ severe ARC will be homeless @ $12,000 per year per client (based on Shanti model)	268	$3.22m	384	$4.6m	522	$6.26m	681	$8.17m	863	$10.35m
Shared/Referral: (b) 10% of people with AIDS/Severe ARC will need shared housing (San Jose model) @ $500 per client per year	537	$268,500	768	$384,000	1,043	$521,500	1,362	$681,000	1,725	$862,500

(2) Services, Patients, and Cost (continued)

Program Component	1987 Patients	Est. Cost	1988 Patients	Est. Cost	1989 Patients	Est. Cost	1990 Patients	Est. Costs	1991 Patients	Est. Costs
5. Sub-acute Care										
(a) Residential Hospice (Coming Home model) 10% of people with AIDS/ARC will utilize this service @ $140 perday $51,100 per year	537	$27.44m	768	$39.24m	1043	$53.3m	1362	$69.60m	1725	$88.15m
(b) Skilled Nursing Facility 5% of people with AIDS/Severe ARC will utilize this service @ $225 per day = $82,125	268	$22m	384	$31.5m	522	$42.8m	681	$55.9m	862	$70.8m

(2) Services, Patients, and Cost (continued)

Program Component	1987 Patients	Est. Cost	1988 Patients	Est. Cost	1989 Patients	Est. Cost	1990 Patients	Est. Costs	1991 Patients	Est. Costs
6. Home Health Nursing and Attendant Care										
(a) Intermittent Nursing Services @ $30 p. hr x 10 hrs. per week = $15,600 per year for 15% of AIDS/Severe ARC	269	$14.18m	384	$5.95m	522	$8.15m	681	$10.6m	862	$13.45m
(b) Attendant Care Service for 15% of AIDS/Severe ARC x20 hrs per week @ $12 per hour = $12,480 per year	806	$10.1m	1,152	$14.38m	1,565	$19.53m	2,043	$25.5m	2,588	$32.3m
(c) Home Support Services 12% of AIDS/Severe ARC will be served by volunteer home support services (1 volunteer co-ordinator / 50% clericla assistant @ $50,000 per year = 200 volunteers to 100 clients = $500 per client per year	644	$322k	922	$461k	1,252	$626k	1,634	$817k	2,070	$11.04m

(2) Services, Patients, and Cost (continued)

Program Component	1987 Pati-ents	Est. Cost	1988 Pati-ents	Est. Cost	1989 Pati-ents	Est. Cost	1990 Pati-ents	Est. Costs	1991 Pati-ents	Est. Costs
(d) Critical Mental Health Services in the home - 1% of patient population will require careful monitoring for OBS & suicidal ideation - 1 consultant & psychotherapist @ 80 per hr. x 52 sessions = $4160 per year	54	$225k	77	$320k	104	$433k	136	$566k	172	$716k
7. Emotional Support 100% of people with AIDS/Severe ARC 1 professional mental health volunteer coordinator per 60 volunteer 'buddies' & psychotheraputic consultant @ $60,000 per year = $1,000 per client	5,370	$5.37m	7,680	$7.68m	10,431	$10.43m	13,620	$13.62m	17,250	$17.25m

Health Policy and Research Foundation
Estimate Service Utilization and Cost of Care
for HIV infection in California in 1987
for 5370 living AIDS/Severe ARC patients

(A) Service Overview

Percentage of living patients in stages I - IV, HIV infection	Service Component	Estimated Cost per year per patient	Estimated numbers of patients utilizing service at one time	Annual cost for 1987	% of total budget
6% of HIV infected stages III & IV	Inpatient care	$319,375	322	$102.8m	55.5%
100% HIV stages III & IV	Case management	$1,000	5,370	$5.37m	3%
50% of HIV infected stages III & IV	Outpatient care for HIV symptomatic (stagesIII & IV)	$1,500	2,685	$4.03	2.2%
5% of stages III & IV	Residential services (Shanti model)	$12,000	268	$3.22m	1.5%
10% of HIV stages III & IV	Residential services Shared housing & referral	$500	537	$269k	.2%

Health Policy and Research Foundation
Estimate Service Utilization and Cost of Care
for HIV infection in California in 1987
for 5370 living AIDS/Severe ARC patients

(A) Service Overview (continued)

Percentage of living patients in stages I - IV, HIV infection	Service Component	Estimated Cost per year per patient	Estimated numbers of patients utilizing service at one time	Annual cost for 1987	% of total budget
10% of HIV stages III & IV	Residential Hospice Facility (Coming Home Model)	$51,100	537	$27.44m	15%
5% of HIV stages III & IV	Skilled Nursing Facility	$82,125	268	$22m	12%
1% of HIV stages III & IV	Critical Mental Home Services	$4160	54	$225k	.1%
5% of HIV stages III & IV	Home Health Skilled Nursing	$15,600	268	$4.18m	2.3%
15% of HIV stages III & IV	Attendant Care	$12,480	806	$10.1m	5%
12% of HIV stages III & IV	Home Support Services	$500	644	$322k	.2%
100% of Stages III & IV	Emotional Support Services	$1,000	5370	$5.37m	3%
				$185.326m	100%

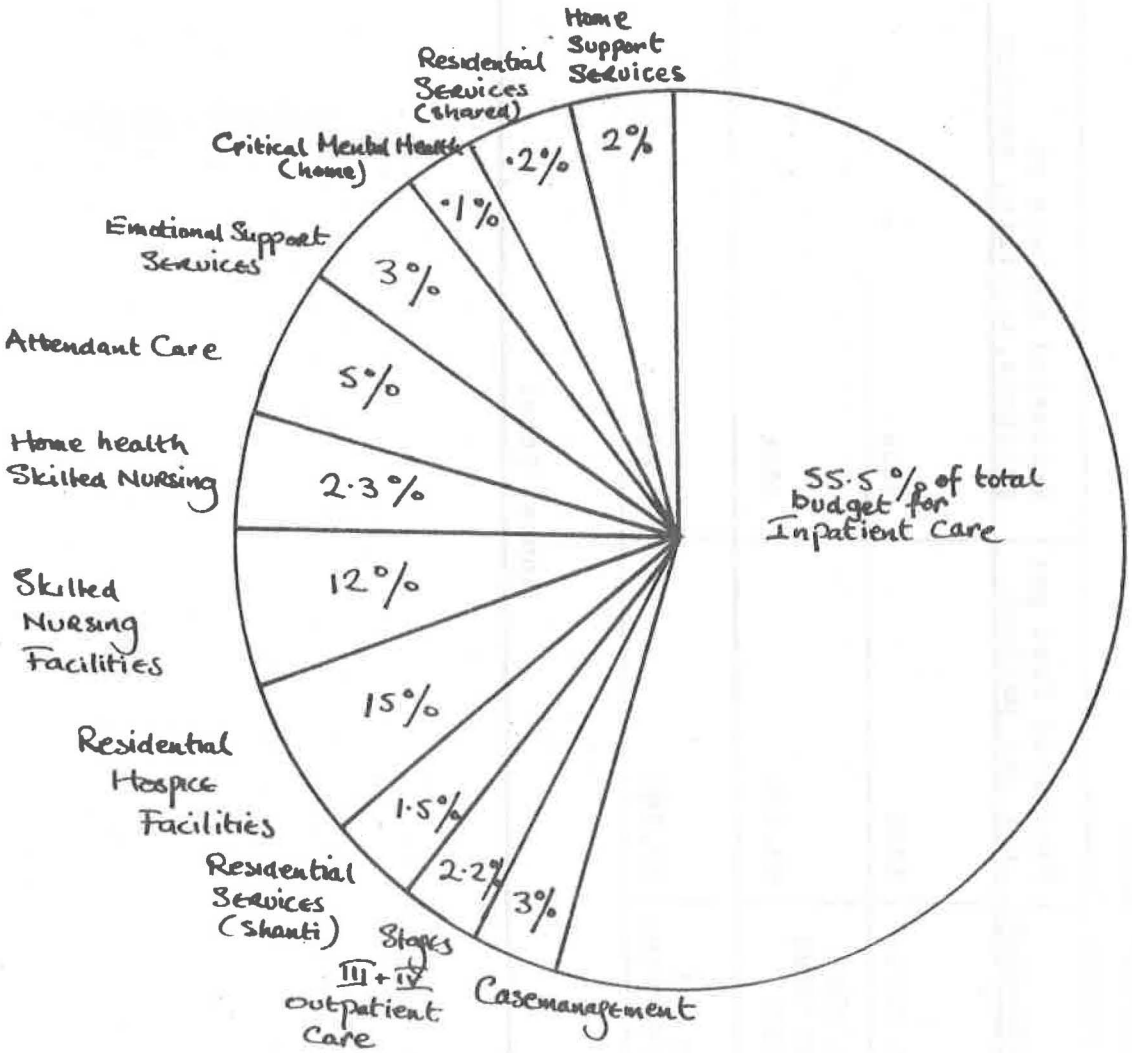
Health Policy and Research Foundation
Estimated Service Utilization and Cost of Care
for HIV Infection in California in 1987

(B) Anticipated Outpatient and Medication Costs

Percentage of Living Patients Stages 1-4	Service Component	Estimated Cost per year per patient	Estimated numbers of patients utilizing service	Annual Cost
100% of HIV infected Stages I & II	Outpatient care	$600	300k	$180m
100% of HIV infected Stages I & II	Outpatient care (Medication/drug intervention)	$3,000	300k	$900m
75% of HIV stages III & IV	Medication and Drug Intervention	$9,000	4,028	$36.25m
			Annual Total	$1.116b

CALIFORNIAS WAR ON AIDS

SERVICE UTILISATION BASED ON COST OF CARE FOR HIV INFECTION FOR 1987.



estimated budget for care in 1987-$185 m.

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Goal - 6 To develop a model of comprehensive care to patients with HIV infection which could be used in any county in California. This will be achieved through developing a service matrix and case management system through designated Regional AIDS Treatment Centers.

This model will focus on providing inpatient and outpatient services with an extensive network of complementary services designed to maximize the potential of patients maintaining themselves well outside of acute care settings.

If outpatient care and various program components are missing in certain regions, the estimated percentage of impatient care will increase accordingly with a significant increase in the anticipated cost of care.

A. Program Components for HIV Infected Stages I and II (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 attitudinal changes. (The majority of patients in the target group will be employed and active and will need minimum medical intervention). This will be achieved through expanding the programs at Confidential Testing Sites and providing immediate access to medical, psycho-social and AIDS prevention services including clinical drug trials.

1. Confidential Testing of Blood

The demands on the 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 this program 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 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.

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 within 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 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 Intervention and Prevention Programs for HIV Infection in Stages I and II.

A patient is referred by the Confidential Testing site or another physician to an identified AIDS Treatment Center. Here a physician will perform an extensive medical examination. 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 tothis 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, with input from the Computerized AIDS Information Network or the proposed statewide AIDS Clearinghouse.

There are an estimated 250,000 HIV infected individuals in California. The drug Ribaviran 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 $3,000 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 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. Intravenous Drug Users in HIV Stages I and II.

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.

4. Physician Education and Access to Services

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. Physicians should be educated to counsel HIV infected individuals and should be provided with technical assistance for establishing clinical drug trials with their patients.

5. 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 this section. Special psycho-social programs will need to be developed for infected children, hemophiliacs and their families, infected prisoners will need counseling, risk reduction programs, and treatment services similar to those already outlined in this section.

B. Programs Components for HIV Stages III and IV (lymphadenopathy and symptomatic infection): Developing Regional AIDS Treatment Centers

The Regional AIDS Councils

The goal of this section is to plan for the necessary continuum of care for people with HIV infection through regional collaborative forums called Regional AIDS Councils, and to implement the planning through regional AIDS Treatment Centers.

The Importance of Regional Planning for Long Term Health Care

In developing a long range strategy for dealing with the 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 system of Sexually Transmitted Disease regions currently utilized by the California Department of Health Services' Office of AIDS, does not reflect AIDS 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 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 to improve cooperation between the counties.

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 preliminary regional configuration of counties and for AIDS related services based on the existing networks of service providers and patients needs. Input from the counties on the final configuration is vital.

The AIDS Treatment Centers

The overall goal of this program is to establish comprehensive care through a case management system for people with HIV infection stages III and IV, permitting patients to maintain the quality of their lives in home environments as long as possible.

Once established, the regions should develop their own AIDS Treatment Centers based at hospital facilities. 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 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 (see Appendix 1, 2, 3, 4).

1. Integrated and comprehensive services will be provided at the 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 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(see Appendix 4).

   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 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 is useful.

(c) Residential programs based on the San Francisco Shanti model.

(d) Shared housing programs based on the San Jose Catholic Social Services model.

(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.

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.

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. They 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.

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

(See Appendix 3 on AIDS Treatment Center Complete Service Matrix)

Confidentiality Issues

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.

It should be emphasised that the confidentiality surrounding patient information be observed and that the patient have the final say as to what information is disclosed and to whom. As stated earlier for medical, psycho-social, and prevention standards for

HIV infection in stages 1 and 2, informed consent must be obtained not only for release of HIV antibody test results but for disclosure of information about the HIV infection of the affected individual. Such confidentiality would follow accepted procedures presently mandated by statute for release of medical information, i.e. a signed written consent for release of information, etc. The authorization for release of information should be required for everyone working on the case management team for every release of HIV information, have a stated period of effectiveness, and be revocable by the patient at any time.

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

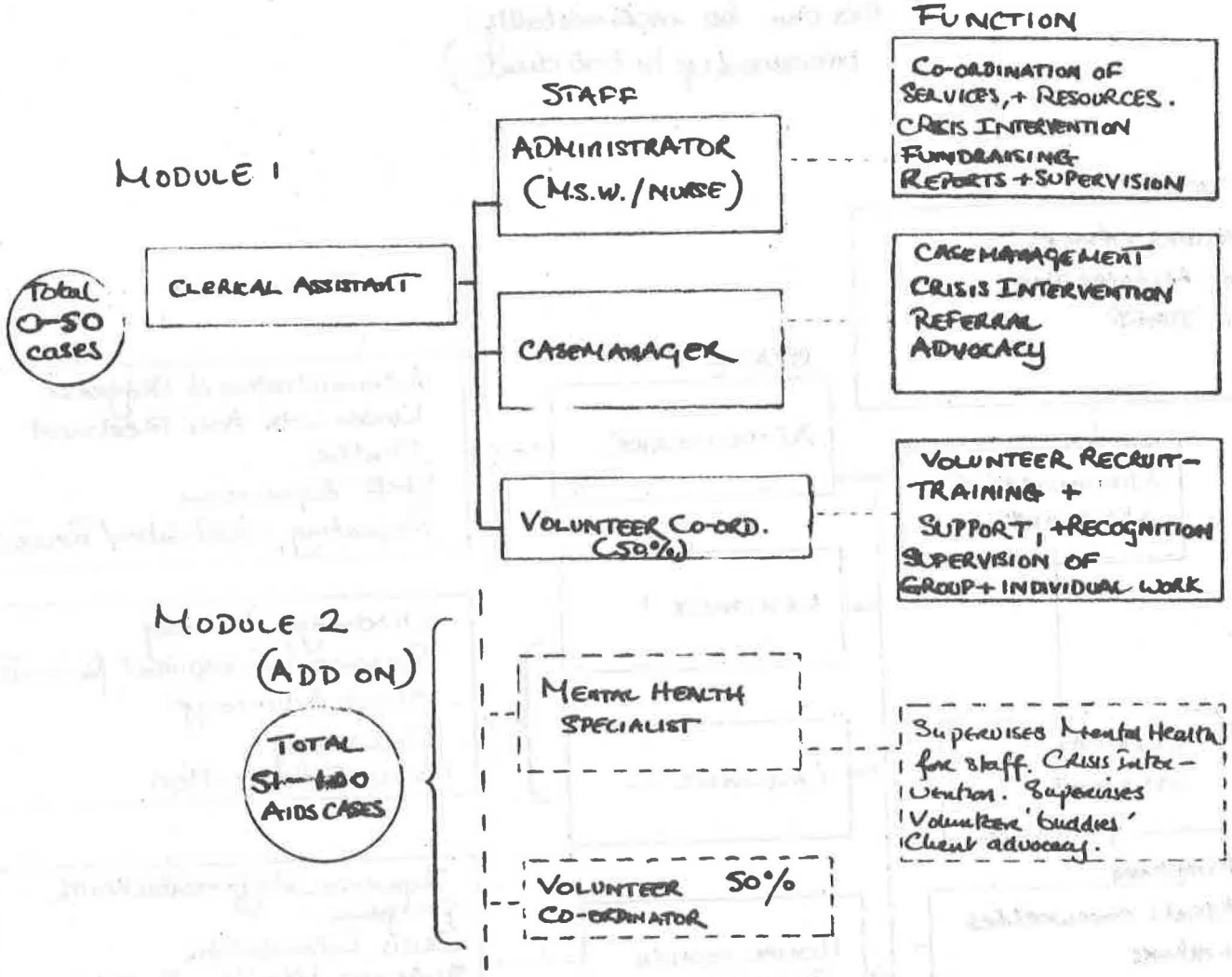
13. Professionally staffed comprehensive program of volunteer recruitment, training and support should be operated in conjunction with the AIDS Treatment Center.

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 through by counseling, befriending, (based on San Francisco's Shanti model) or volunteer practical support including light household duties, shopping and providing transportation for patients.

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 Project 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 recruitment; 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.

APPENDIX

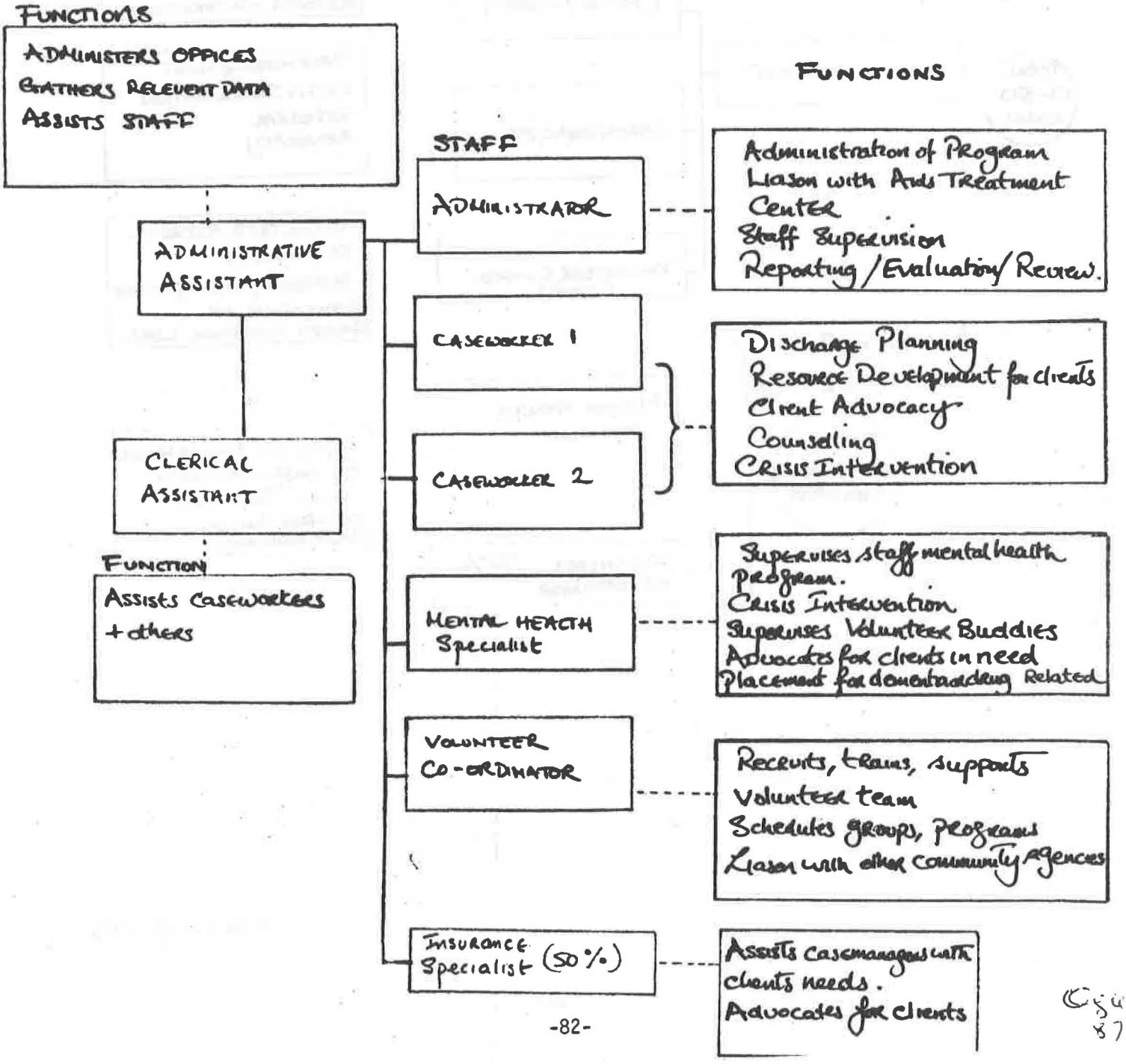
CASEMANAGEMENT MODEL
(Modules 1 + 2)



OGLE 1/5/87

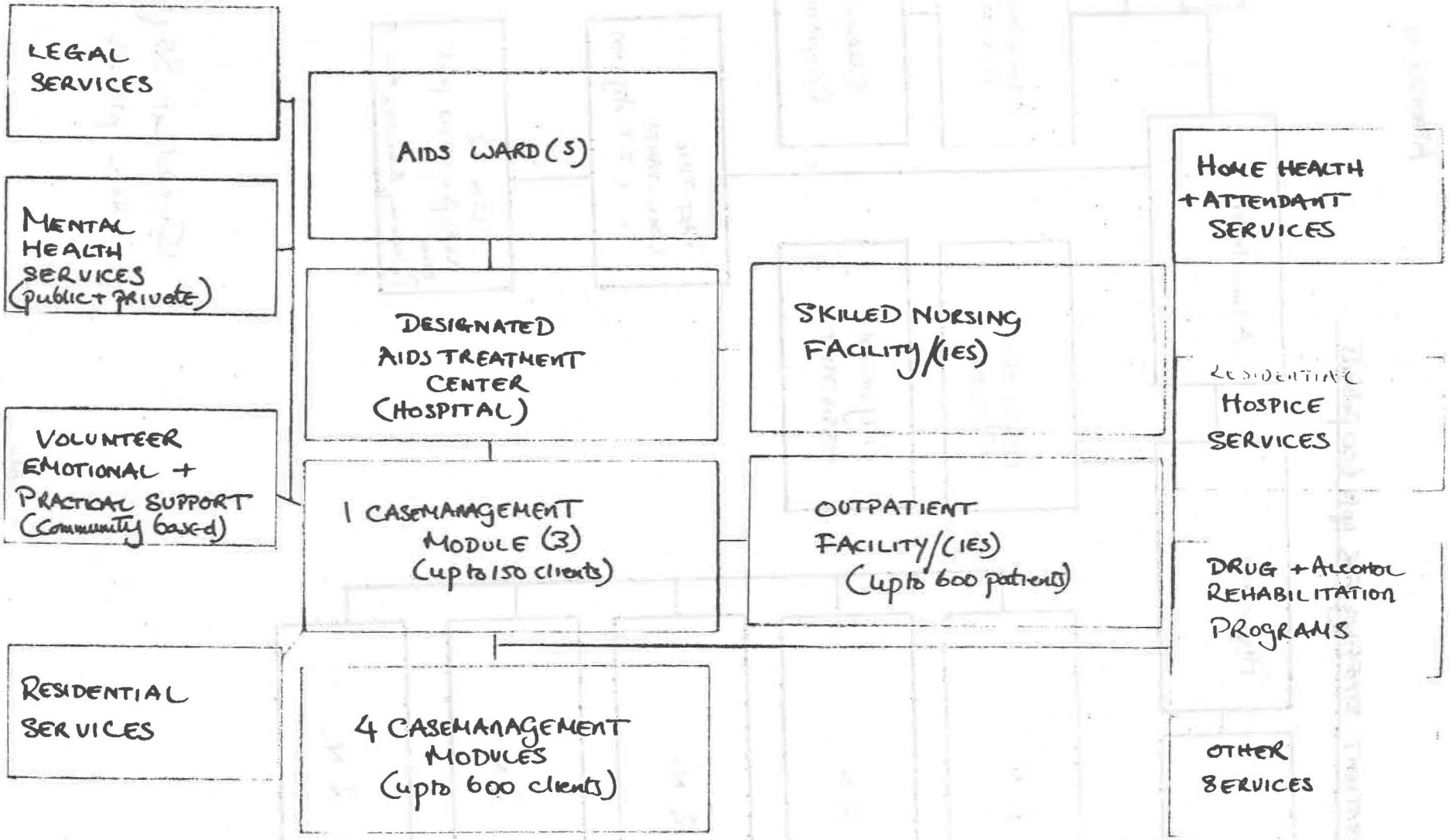
CASEMANAGEMENT MODULE 3

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



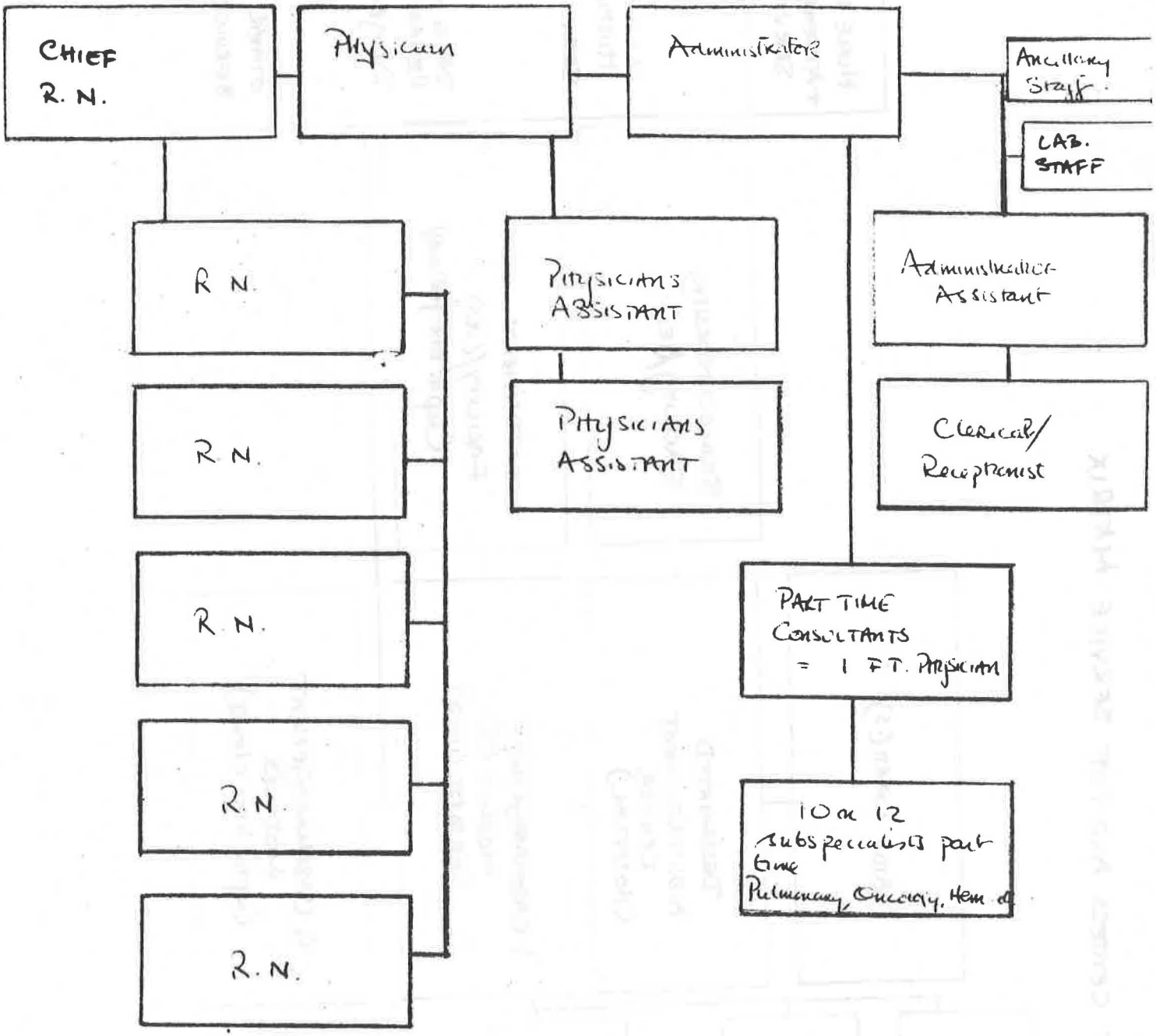
Appendix 3

AIDS TREATMENT CENTERS AND THE SERVICE MATRIX



APPENDIX 4

AIDS OUTPATIENT STAFFING FOR up to 600 patients



Outpatient Staffing
600 patients

CGG
'87

APPENDIX 5

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
Atlanta GA 30333

404 329-3775
FTS 236-3775

December 31, 1986

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,

Meade Morgan

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

REPORTED:

Year	Cases Diagnosed	Deaths
1981 & before	67	21
1982	202	66
1983	639	253
1984	1219	608
1985	2136	1136
1986	2129	1122

PROJECTED:

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

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

REPORTED CASES:

Year	San Francisco	Los Angeles	Other California
1981 & before	52.2	32.8	14.9
1982	53.0	35.6	11.4
1983	48.0	39.3	12.7
1984	48.6	35.7	15.7
1985	42.6	38.2	19.2
1986	45.1	37.2	17.7
PROJECTED CASES:			
1986	42.8	37.3	19.9
1991	33.5 (29.4, 37.7)*	35.7 (31.4, 40.1)*	30.8 (26.4, 35.5)*

*68% confidence bounds are given in parentheses.