CAEAR
CITIES ADVOCATING EMERGENCY AIDS RELIEF

April 16, 1998

The CAEAR Coalition

1413 K Street N.W.

Suite 700

Washington, DC

20005

T 202 789 3565

F 202 789 4277

caearindc@aol.com

Ms. Sandra Thurman
Office of National AIDS Policy
736 Jackson Place, NW
Washington, D.C. 20503

Dear Sandy:

It was great to see you the other day. I love your alarm clock! Seeing you laugh made my day. I worry about you a lot -- I know that this work is hard. But, for what it's worth, you ARE making a difference!!!

I'm very excited to have the opportunity to work with you and Todd again (even if it means working in Washington, D.C.). The CAEAR Coalition is committed to being present and engaging in ways we've not been in recent months. I'm counting on our collective history to help us do the work we must do to accomplish the things that people living with HIV/AIDS need accomplished in the next few months.

Take care of yourself and your blessings.

Yours in the struggle,

Phill Wilson
Interim Executive Director

PW/tt

Enclosures

CAEAR
CITIES ADVOCATING EMERGENCY AIDS RELIEF

$570 MILLION NEEDED IN FY 99 FOR CARE ACT TITLE I

Hope, not hoax – new treatments require new resources.

- The CAEAR Coalition is requesting a minimum of $570 million in FY 99 funding for TITLE I of the Ryan White CARE Act. **This would be an increase of $105 million over FY 98.** The promise of new treatments, such as protease inhibitors, is inextricably linked to the primary health care and support services funded under TITLE I.

- The 51 metropolitan areas eligible in FY 99 to receive emergency assistance under TITLE I provide care to at least 74% of all reported cases of AIDS in the United States. The infrastructure of care services created under TITLE I continues to be a critical component of AIDS care in America.

- According to the Centers for Disease Control and Prevention, AIDS prevalence will continue to increase. This fact underscores an increasing need for medical and other services for people living with AIDS. As the number of AIDS deaths has begun to decrease, the number of people living with AIDS has grown. Twenty percent of TITLE I clients annually are new cases.

Expanded services are required by new federal HIV Treatment Guidelines -- 59% of TITLE I services provide primary health care.

- A decade and a half of research has brought significant breakthroughs in the treatment of HIV. These breakthroughs have led the U.S. Public Health Service to recommend, as the proposed standard for medical care, viral load testing and use of combination therapies, including protease inhibitors.

- The new standards of care require that TITLE I areas ensure access to medical care, the new anti-HIV drugs and the support services that enable successful adherence.

- The first step in accessing the new combination therapies is a physician's visit, followed by diagnostic tests, including the viral load test, and then for many, a prescription – all services provided with TITLE I dollars. Funding for drugs without funding for the mechanisms which make those drugs available is an ineffective policy and a cruel hoax for those who stake their lives on the hope of these new AIDS treatments.

- Currently, the lowest estimated cost for measuring a person's viral load is $100 per test, and quarterly monitoring is recommended. Test costs, in some locales, are as high as $250 per test. The Health Resources and Services Administration (HRSA) estimates there are 350,000 TITLE I clients and that at least 30% of these clients are expected to use TITLE I funding to pay for viral load testing. **To provide quarterly viral load testing for these TITLE I clients requires a minimum FY 99 increase of $42 million.**

- The new treatments are often complicated and have the potential for severe side effects. A person who fails to take these medications as prescribed runs the risk of developing resistant viral strains. Close monitoring by a physician, provided with TITLE I funding, is required.

- TITLE I services are predominantly used by symptomatic people with AIDS who require significantly more – and more complex – medical visits. The number of primary care exam slots for HIV care also increases as people with HIV live longer. A goal of TITLE I communities is to expand access to care and treatment at an earlier stage of disease -- an unachievable standard for most communities with current resources.

- The provision of medical health care services accounts for the expenditure of 59% of Title I funds. This includes not only physicians visits, but tens of millions of dollars for the direct purchase of medicines, and millions more transferred from TITLE I to TITLE II AIDS Drug Assistance Programs (ADAPs). In FY 97, 10% of TITLE I funds, or $41,059,269, was transferred to ADAP -- based on local priorities.

- The need for services that are traditionally not considered primary medical care, such as nutrition and case management services, has also grown with the use of the new combination therapies. The reason is simple: many of these services are critical to a person's ability to adhere to an effective drug regimen. **The CAEAR Coalition requests a very conservative increase of $11 million to address the expansion in services, other than viral load testing.**

Epicenter EMAs struggle to respond to flood of new patients seeking medical care.

- **New Clients.** HRSA estimates that 20% of TITLE I clients every year are new clients. TITLE I communities across the country have documented client increases ranging from 13% to as high as 74%. **A minimum FY 99 increase of 10% in TITLE I funds, or $46 million is required to provide for these new TITLE I clients.**

New TITLE I Areas in FY 99 -- existing areas continue to lose funding.

- **In FY 99, two new areas become eligible for TITLE I.** Both Norfolk, Virginia, and Las Vegas, Nevada, have become eligible for TITLE I emergency assistance in FY 99, increasing the total number of TITLE I communities from 49 to 51. **To reflect that growth in TITLE I areas, the CAEAR Coalition is requesting a minimum increase in FY 99 funding of $6 million.**

- **In FY 98, fifteen TITLE I areas lost funding as compared to the previous year.** Despite modest increases in CARE Act funding overall, some, though not always the same, TITLE I communities have lost funding three of the last four fiscal years in comparison with their previous year funding. Clearly funding for TITLE I of the CARE Act has fallen behind the need to provide increased resources to each and every TITLE I community.

For further information, contact the CAEAR Coalition,
1413 K Street, NW, Suite 700, Washington, D.C. 20005, 202.789.3565, fax 202.789.4277; *or*
The Sheridan Group, 1808 Swann Street, NW, Washington, D.C., 20009, 202.462.7288, fax 202.786.1964

Draft Appropriations Report Language

The Committee has provided $570 million in funding for Title I and $113 million in funding for Title III of the CARE Act. These funding levels are critically important to assuring access to, and successful utilization of, the new anti-HIV drugs and combination therapies.

Title I expands this fiscal year to another two metropolitan areas, providing resources to the 51 U.S. communities where over 74% of all Americans with AIDS have been diagnosed. The CARE Act mandates local control of Title I funds which are allocated to the medical health services and the supportive services that enable individuals to adhere to complex combination therapy that include protease inhibitors. Without adequate funding to these communities hardest hit by the AIDS epidemic, access to the physicians' visits and medical tests required to prescribe the new drugs will remain impossible.

Title III provides HIV-specific funding to 183 community health providers located in urban, suburban and rural parts of the United States,. These directly funded programs allow for early diagnosis and ongoing primary medical care, including the new combination therapies, for 83,000 people infected with HIV. This in turn has reduced hospitalizations by 75%. In addition, Title III funded clinics, with 25% of its clients women of child-bearing age, are uniquely situated to provide the successful AZT intervention that reduces HIV transmission from mothers to infants from 25.5% to 8.3%.

CAeAR

CITIES ADVOCATING EMERGENCY AIDS RELIEF

You are cordially invited to attend
A Cash Bar Reception
On Friday, April 24, 1998
From 6:30 to 8:30 p.m.
In the "Private Reserve" of the

Embassy Row Hilton
2015 Massachusetts Avenue, N.W.
Washington, D.C. 20036

This event is especially for
Members of the CAeAR Coalition
And our Good Friends as we prepare
For our Spring Business Meeting
And Advocacy Days.

Business or Casual Attire Acceptable.
Please RSVP regrets only to Tony Teano
At (202) 789-3565
By April 22, 1998.

We look forward to seeing you!

1875 Connecticut Ave., NW. Suite 700
Washington, DC 20009
(p) 202-986-1300
(f) 202-986-1345

AIDS Action Council

Fax

To: Sandy Thurman **From:** Kerri Dumas, X3030

Fax: 456-2438 **Pages:** 3

Phone: **Date:**

Re: **CC:**

☐ **Urgent** ☐ **For Review** ☐ **Please Comment** ☐ **Please Reply** ☐ **Please Recycle**

• **Comments**

TADD
(copy already filed)

until it's over
AIDS ACTION

April 9, 1998

Secretary Donna E. Shalala
Department of Health and Human Services
615F Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, D.C. 20201

VIA FACSIMILE - URGENT

Dear Secretary Shalala:

On behalf of AIDS Action Council and the 2400 AIDS service organizations we represent, I urge you to immediately request a rehearing of the Desario case before the full Second Circuit Court of Appeals by the filing deadline of April 10th (Desario v. Thomas, No. 97-6027, U.S. Court of Appeals, 2nd Circuit, February 24, 1998). In addition, we respectfully request that the Health Care Financing Administration immediately communicate with state Medicaid programs about the appropriate use of lists; the legal obligation of Medicaid programs to provide medically necessary services to all Medicaid beneficiaries; and the illegality of discrimination against Medicaid recipients based on diagnosis and condition.

The recent decision of the three judge panel of the Second Circuit Court of Appeals poses an immediate threat to the quality and scope of health care of Medicaid recipients living with HIV/AIDS and other chronic and costly health care conditions in all of the states governed by the 2nd Circuit. Since one of these states, New York, is the home to more living AIDS cases than any other state, the ramifications of the decision for the AIDS community are profound. This decision undermines the fundamental principles of the Medicaid statute and erodes the very value of the Medicaid entitlement.

As you are well aware, Medicaid is the major source of health care for men, women and children living with HIV/AIDS and is often the only health care available to these individuals. You are also well aware that life-prolonging but costly drugs are dramatically reducing the mortality and morbidity associated with AIDS. AIDS Action joined the Clinton Administration in opposing the efforts of the Congressional Republican leadership to block grant the Medicaid program and to eliminate the benefit and quality protections available to Medicaid recipients. This court decision, if allowed to stand, would allow state Medicaid programs to deny vital services, including life-saving drug treatments, to eligible beneficiaries solely on the basis of cost. It would be tragic of the major victory of preserving the Medicaid program was undermined by a bad court decision.

1875 Connecticut Ave, NW Suite 700 Washington, DC 20009 P 202 986 1300 F 202 986 1345 www.aidsaction.org

Please take action on the Desario case before a precedent is set that will threaten the gains the nation has made in fighting the AIDS epidemic and will jeopardize the health and lives of people with HIV/AIDS who depend upon the Medicaid program.

Sincerely,

Daniel Zingale
Executive Director

cc: Nancy-Ann Min DeParle
Chris Jennings
Kevin Thurm
Sandra Thurman
Eric Goosby
Dr. Peggy Hamburg
Richard Socarides

Hi Mrs Thurman thank you for your letter of Jan 20, 1998. I know you were beautyfull on the inside for all the work your doing to help people with aids, then last month I saw you on TV talking about your work, and I can see that God has also blessed you to be beautyful on the outside (Smile) I'm sending you this Information. to bring you up to date on some of the work I'm doing to help people.

Brother Bob Israel.

TO WHOM IT MAY CONCERN:

I am in prison, as you can see by my return address. However, I have found useful, fulfulling work even here. I have instigated a program here at this institution to teach BARBERING and COSMETOLOGY. I feel that it can be beneficial everywhere in this system, as well as in state institutions, wherever there are people with no skill with which to make an "honest living".

There is certainly more to BARBERING and COSMETOLOGY than just cutting hair. It involves Anatomy, Physiology, AIDS Awareness and Safety Procedures, and I believe, most importantly, a moral code. Hopefully, by example I instill in my students honesty, pride in achievment, and a sense of the artistry of this profession. It is, I believe, an honorable way to serve, for the hair is a reflection of the inner self, and the way one is groomed speaks to the external world with a definite message. It speaks volumes without a word being exchanged.

Therefore, since appearance is important in the way we are viewed by others, I show my students how their work can help or hinder their customers. If the student understands this concept, how can he fail to take pride in his work. He is making an important contribution to his customers success or failure in whatever endeavor.

I am dedicated to the benefit of my fellow man and to the uplifting of his spirit. I take pride in helping men who have no marketable skill become productive members of society. The program is about helping people, and about making the streets of our nation safe for its citizens. I am writing this letter to ask for your aid and assistance in expanding the program to other institutions in the federal system, and perhaps, even to the various state institutions.

I know how to run the program, but do not know how to promote the program to other institutions. I am, of course, limited by the fact of my incarceration as to what I can do, and require official sanction of some sort to do anything.

Perhaps there is something that you can do to assist the expansion of this program to other institutions. I myself, am willing to do anything and everything possible to see its growth to other institutions. I believe in its benefits and potential for good.

I look forward to hearing from you, your ideas, impressions, suggestions, or criticisms. Please let me hear from you.

Sincerely,

Job Israel

JOB ISRAEL,
PMB-879 - 36245-004
COLEMAN, FL 33521-0879

Hair Science & Beauty NEWS

Hair Science & Beauty News

Minority Media Marketing Publication

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NATIONAL EDITION

MAY/JUNE 1998 Volume 1, Number 1

3570 Olive Street, Lemon Grove, CA 91945
(619) 668-1007, Fax: (619) 668-0778

1998 Hair Designer for the ESSENCE TV AWARDS

A Silent Worker Among the Imprisoned

Job Israel has started cosmetology/barbering programs within the Federal Bureau of Prisoners system. He also teaches classes in sterilization, sanitation, bacteriology and AIDS prevention. Through his efforts, Job Israel helps inmates acquire occupational skills that will give them the resources they need for employment success.

One hundred and seventy-five inmates have graduated from Job Israel's program, saving the taxpayers an estimated $750,000. Presently, he has twelve inmate pupils in his program which saves the state of Florida an estimated $100,000. The reduction of recidivism is a major objective of the correctional system in addition to saving tax dollars.

Job Israel, who started his programs in Fort Dix, New Jersey, has been a model of prisoner for his fellow inmates. He has been congratulated by Connie Mack, U.S. Senator; Sherry J. Moses, Congressional Aide; Alexis M. Herman, Secretary of Labor; and many others. Some of the people who have helped him the most include Congresswoman Carrie Meek, his former high school teacher; Captain Barbara McIntuff, head of security over the prison barber shop; and Warden D.L. Hobbs whose great foresight makes the program work and function with dignity.

Job Israel really shares his thoughts and efforts with everyone who wants to better the American society and bring an end to the cycle that inmates get caught in with their habitual return to prison over and over again.

Job wants to change the way life has been for so many blacks who have no future in today's skilled workplace. His tireless contribution is working miracles among the inmates of the Federal Correctional Complex (Coleman Low) in Coleman, Florida.

Regional Associate Editors

Kevin Wilmore, New Orleans, LA
504-482-8035

Effie Easterwood, Kansas City, KS
816-361-8110

Inez Kennedy, Flat Rock, NC
704-697-0861

Lu Venia Wiggins, Fuquay, N.C.
919-557-5269

La Brown Andrews, Memphis, TN
901-365-0294

Archie Collins, Los Angeles, CA
310-569-9344

Brent Jones, Los Angeles, CA
213-935-2799

Danette Robinson, Sacramento, CA
916-395-4897

Delores Porter, St. Louis, MO
314-865-4607

Juanita Jones, Forest, MS
601-469-1705

Rudolph Townsel, New York, NY
212-874-4816

Cheryl Morrow, New Yo
212-491-0802

Joyce Scott, Atlanta,
770-267-1142

Pam Davis, Riverdale
770-907-0095

Tariq Madyun, Madiso
205-461-4264

Mary Lockett, Anniston
205-237-4031

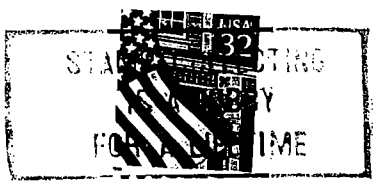
Horace Barkley, Detro
313-864-2540

Lesa Martin, Detroit
313-837-0913

Julia Smith, Clinton,
301-868-0188

Charles Thompson, Den
303-355-9074

Joe Israel 36245004
FCC Coleman (Low)
P.O. Box 879
Coleman Fl 33521



Mrs Sandra L. Thurman
Director Office of National Aids Policy
The White House
Washington D.C. 20500

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

17 April 1998

Sandra Thurman, Director
Office of National AIDS Policy
736 Jackson Place, NW
Washington, DC 20503

Dear Sandy:

Whatever it takes, you've certainly got it to knock us off the front page and reduce coverage of the board meeting to a caption!

See the attached clipping (I thought you should have a clearer copy that the fax!).

But, seriously, on behalf of the board of directors of the San Francisco AIDS Foundation, please accept my personal gratitude for your contribution to our March meeting. We were honored your schedule allowed a visit and were heartened by news of the ongoing discussions. Somehow, in the end, I hope we prevail.

Thank you for efforts on behalf of all people living with and affected by HIV. I'm glad you're in our corner. Besides, it makes it so much more interesting.

And thanks again for sharing your insights with us.

Sincerely,

Paul

Paul Wisotzky
Chair, Board of Directors

10 UNITED NATIONS PLAZA
SAN FRANCISCO, CALIFORNIA 94102-4901
(415) 487-3000

Exchange program

Photo: Credit

AIDS Czar" Sandra Thurman was a surprise guest at the San Francisco AIDS Foundation's board meeting Wednesday, March 25. Thurman (center, flanked by SFAF Board Chair Paul Wisotzky on the left and SFAF Executive Director Pat Christen) was in town for the AIDS Update Conference, but stopped by the meeting to reiterate her support for needle exchange, to acknowledge that she and the Clinton Administration's "Drug Czar" Barry McCaffrey have differing opinions on the matter (joking that their conflict is referred to as "Czar Wars" inside the Washington Beltway), and to urge those interested in slowing the epidemic to write to Secretary of Health and Human Services Donna Shalala and ask her to end the ban on needle exchange.

About a dozen members of the public also attended the board meeting, which lasted more than five hours, without incident. Throughout the meeting board members and SFAF staff vowed to refocus their energies on addressing the housing crisis faced by people with HIV and AIDS. ▼

Teng zapped at finance meeting

by Cynthia Laird

An otherwise staid meeting of the Board of Supervisors Finance Committee was spiced up Wednesday, April 1, when ACT UP/Golden Gate activists zapped committee chair Mabel Teng, calling on her to schedule a hearing for Supervisor Tom Ammiano's proposed legislation regarding nonprofit accountability. After several minutes of comments, Teng did promise she would schedule the hearing this month; the legislation must be heard by the Finance Committee before it can proceed.

Teng was apparently tipped off to the action: two San Francisco police officers were stationed outside of her office shortly before the 1 p.m. meeting began, and she was escorted upstairs to the committee room by an officer. No arrests were made, and the activists left peacefully after the disruption.

Teng also denied telling a reporter from the *Independent* that she was going to propose alternative legislation to Ammiano's, a move that infuriated activists when they read about it earlier this year. However, despite her statement "I have not talked to the *Independent*," a reporter from that newspaper who was at the committee meeting indicated he had talked with the supervisor.

"You're killing people with AIDS, Mabel," said activist Jeff Getty, as he and others unfurled banners when they disrupted the meeting. Soon, they began chanting, "Mabel, Mabel, don't call her honey, she's just in it for the money."

Added ACT UP member Stephen LeBlanc, "We want to know when you'll schedule the hearing."

"I told you I would schedule a hearing in April," a visibly nervous Teng said as several activists stood in the committee room. She added that "the person who requested the hearing" only left her an e-mail message two days ago regarding the matter.

Last month, a 20-member task force convened by Ammiano came up with several recommendations to open up nonprofits that receive city funds. Specifically, areas of concern to activists center around financial records and access to nonprofit board meetings. The task force was composed of activists, and nonprofit administrators and board members. Many of the recommendations have been praised by local officials and activists, and Ammiano has forwarded the matter to City Attorney Louise Renne's office to come up with draft legislation.

On Monday, March 30, Teng's office told the *B.A.R.* that no hearing date has been set. ▼

SF study: few high-risk gay men get HIV prevention referrals

by Cynthia Laird

A study of high-risk clients in San Francisco who test negative for HIV has revealed that men who have sex with men (MSM) are less likely to get referred to counseling and prevention services than injection drug users (IDU).

Dr. Rani Marx, with the city's Department of Public Health (DPH) epidemiology and evaluation unit, revealed the findings at the Thursday, March 26 meeting of the HIV Prevention Planning Council, prompting considerable surprise among members.

"I'm astounded," said Steven Sams, community co-chair.

Marx said the San Francisco study was done in an effort to gather data, not to judge the job counselors are doing.

"No one's looked at referrals, particularly among high-risk negatives," Marx said during her presentation, which included data from two studies. The first study, which had a greater number of people sampled, was conducted between January and October 1995. The study was an analysis of San Francisco counseling, testing, referral, and partner notification (CTPRN) data on 7,010 people who received seronegative confidential test results. Of those, 5,595 (or 80 percent) provided behavioral risk information, and it was those people investigators focused on.

The study found that just over 20 percent of the MSM population received prevention referrals, while 50 percent of the IDU population received prevention referrals. Slightly more than 20 percent of the high-risk females received prevention referrals, according to the study. Marx said that in the study, a referral had to be to a place where people would receive something. She also said it was not the job of investigators to judge what was right or wrong about why prevention referrals were or were not given. But her comments pointed to the need for additional training of counselors.

"The percentage of people getting referrals is low. Counselors say people refuse referrals all the time and that's just not true," said Marx. The information on counselor reasons was gathered at one site during a shorter period of time, with 747 clients.

One surprising aspect of the study was the reasoning counselors gave for not providing referrals. Marx said that information for 52 percent of the sample revealed counselors did not provide referrals to people who said they were practicing safe sex 100 percent of the time within the past year. However, Marx said that data revealed 86.6 percent of those were not, in fact, practicing safe sex 100 percent of the time in the last year. The counselors at that site felt it would break rapport to provide referrals to clients who had more recently been practicing safe sex.

"We know from the literature that people relapse into unsafe practices, so the question is what is the appropriate position to take vis a vis people who recently are practicing safe sex and safe injection but who may not have in the past year," Marx told the *B.A.R.*

Second study

Marx also discussed preliminary findings from a second study that will probably be completed this summer. She emphasized that the sample is small, with only 46 interviewees so far. The study is looking at accessing prevention services after HIV counseling and testing among high-risk seronegatives. The study is being conducted at four confidential test sites in the city and people must have received at least one HIV prevention referral and not be practicing 100 percent safe sex or safe injection. Participants were interviewed over the phone several weeks after getting the test result to see if they had, in fact, accessed the referral.

The good news, Marx said, was that 76 percent of those who have been interviewed had complete recall of receiving the referral. On the downside, the most common barrier to actually going to the referral was the catch-all "no time" excuse, which was reported by 38 percent of those interviewed, who did not access the referral.

Both studies relied on self-reporting of those interviewed, which has an inherent error factor, Marx said, although she added it's about the only way to obtain the information. ▼

Rick Gerharter

Rani Marx

SF AIDS FOUNDATION

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

17 April 1998

Sandra Thurman, Director
Office of National AIDS Policy
736 Jackson Place, NW
Washington, DC 20503

Dear Sandy:

I wanted to thank you again for taking the time to address our board of directors at their meeting in March. As always you were cogent, persuasive and entertaining.

And it didn't hurt that the B.A.R. editor was there to absorb it and be impressed! You're doing a great job and we're lucky to have you there.

How are those training rides coming along?

Fondly,

Pat

Pat Christen
Executive Director

- Found a Chanel backpack yet? ✌ Pat

10 UNITED NATIONS PLAZA
SAN FRANCISCO, CALIFORNIA 94102-4901
(415) 487-3000

Executive Women in Government

April 15, 1998

Ms. Sandra Thurman
Director, Office of National AIDS Policy
White House Office for Women's Initiatives and Outreach
708 Jackson Place, NW
Washington, D.C. 20503

Dear Ms. Thurman,

Thank you so much for taking time from your busy schedule to speak to the Executive Women in Government Association. We thoroughly enjoyed your talk.

Enclosed you will find a copy of the letter we sent to the Atlanta Fulton Public Library in Atlanta, Georgia transmitting your donation of the Women in the Arts. We hope that the users of the library enjoy it.

Sincerely,

Judy England-Joseph
Secretary
Executive Women in
Government
2208 Glasgow Road
Alexandria, Virginia 22307

Enclosure

Executive Women in Government

April 15, 1998

Atlanta Fulton Public Library
1 Margaret Mitchell Square
Atlanta, Georgia 30303-1089

Attn: Mrs. Julie V. Hunter

In December 1997, Sandra Thurman spoke to the Executive Women in Government Association. When we have guest speakers, it is our practice to donate a book on women in the arts to the library of their choice. Ms. Thurman asked that we make that donation to your library, and we are pleased to carry out her wishes.

Enclosed is the book. We hope that the users of your library enjoy it.

Sincerely,

Judy England-Joseph
Secretary
Executive Women in
Government
2208 Glasgow Road
Alexandria, Virginia 22307

Enclosure

cc: Sandra Thurman

SMAP santa monica AIDS project

April 15, 1998

Dear Friend, Mr Thurman,

As one of our major supporters, I know that you like to be kept informed of latest developments in the fight against AIDS. I enclose a report from the State Office of AIDS, which gives the latest news about the shifting, accelerating HIV epidemic in our State. As the AIDS epidemic continues to outmaneuver our best efforts, detailed information like this about the needs of people with HIV and AIDS is desperately needed.

At Santa Monica AIDS Project, we share many of the concerns listed in the Report. More than 60% of the people we serve face not only AIDS but also chronic mental illness, homelessness or are addicted to substances. For them, AIDS is one more item on a long and tragic list. Our HIV testing service has a three-week waiting list, only six months after funding for HIV testing on the Westside was slashed. Low cost housing continues to be a pressing issue, not only for people with HIV. To access HIV medical services, people face a long journey east.

To address these issues, SMAP works in close collaboration with our sister agencies. With Westside Women's Health Center, we will continue to lobby for increased funds for HIV testing. With Venice Family Clinic, we will create the Westside's first HIV specialty clinic. These are just two examples of the daily connections we make in support of people with HIV, bridges built between agencies which the State's Report highlights as essential as needs grow and resources shrink.

I hope that you find the Report useful. Please do not hesitate to call me with any questions you may have – and thank you for your continuing support for people with HIV and AIDS.

Sincerely,

Hywel W. Sims
Executive Director

2020 SANTA MONICA BOULEVARD, SUITE 190 • SANTA MONICA, CA • 90404
(310)586-SMAP • FAX: (310)586-7644
E-MAIL: smaprus@aol.com

STATE OF CALIFORNIA
STATEWIDE COORDINATED STATEMENT OF NEED

A Collaborative Statement of California's CARE Act Grantees and Persons Living with HIV/AIDS

March 1, 1998

Prepared by:
CALIFORNIA DEPARTMENT OF HEALTH SERVICES
OFFICE OF AIDS

CALIFORNIA STATEWIDE COORDINATED STATEMENT OF NEED

TABLE OF CONTENTS

A. Executive Summary

The state of California - diverse, complex, and geographically vast - is the most populous state in the nation, with a July 1997 state population estimate of 32.9 million persons. As of December 31, 1997, a cumulative total of 104,638 cases of AIDS had been reported in California, and of these, 66,263 persons had died. While 12% of all Americans live in California, the state currently accounts for 17% of all cumulative AIDS cases thus far reported in the U.S.

Through the groundbreaking federal legislation known as the Ryan White Emergency CARE Act, California receives substantial support for an broad array of primary health and social services for persons living with HIV/AIDS. This funding is allocated under several different 'Titles', and includes support for services ranging from basic medical and psychosocial care to innovative approaches to reaching and serving HIV-affected populations. At the present time, California has 54 separate CARE Act grantees, including 9 Title I regions, 1 Title II grantee, 20 Title IIIb grantees, 4 Title IV grantees, 14 Part F SPNS programs and 6 Dental Reimbursement Programs. Each grantee and region conducts its own local needs assessments on a broad range of care and service issues.

In 1997, the U.S. Health Resources and Services Administration (HRSA) - the federal agency that oversees the CARE Act Program - enacted a legislative mandate requiring that CARE Act grantees develop a Statewide Coordinated Statement of Need (SCSN) by early 1998. The Office of AIDS, as the Title II CARE Act grantee, convened the process and coordinated input from California's CARE Act Grantees. The purpose of the SCSN was to bring Ryan White-funded providers together to integrate the findings of their various needs assessments, and to identify significant cross-cutting issues and challenges confronting HIV service provision. The SCSN document was to include a set of overarching goals that could guide the future of HIV/AIDS planning and service delivery in each state, and that would begin a process to prioritize needs across the entire spectrum of CARE Act-funded services.

In its role as coordinating agency, the Office of AIDS implemented a six-part SCSN process beginning in mid-1997. This process included the following elements: 1) Formation of a Steering Committee composed of CARE Act grantees and persons living with HIV to supervise and monitor preparation of the SCSN; 2) Development and distribution of a common questionnaire for California counties on SCSN-related topics, for which counties convened CARE Act grantees in their regions to compile and summarize local needs assessments and to prepare a unified set of findings and recommendations; 3) Sponsorship of three forums for people living with HIV in California, including a forum for women and another for people of color; 4) Sponsorship of a meeting among representatives of State programs and agencies involved in HIV services and service planning; 5) Appointment of a contracted technical writer to compile these findings into a draft SCSN document; and 6) Organization of subsequent series of statewide teleconferences to discuss the SCSN draft, and incorporate feedback from CARE Act grantees statewide.

While prepared by the Office of AIDS, the following document - California's first Statewide Coordinated Statement of Need - represents the synthesis of input from CARE Act grantees, service providers, California state agencies and programs serving HIV-positive individuals, and interested public individuals. This document is not a policy statement developed by the Office of AIDS, it is a summary of perspectives and gives a voice to the concerns of persons living with HIV. The SCSN

became a unique opportunity to improve the quality and scope of services to persons living with HIV by examining the overarching trends, concerns, and cross-cutting issues that confront providers of HIV/AIDS service and care in this diverse and multi-faceted state.

B. Introduction: The California SCSN Preparation Process

Because of its size, diversity, and complexity, preparation of a Statewide Coordinated Statement of Needs (SCSN) presented a special challenge for California. Our state alone has 54 separate CARE Act grantees, including 9 Title I regions, 1 Title II grantees, 20 Title IIIb grantees, 4 Title IV grantees, 14 Part F SPNS programs, and 6 Dental Reimbursement Programs, and each grantee and region conducts its own local needs assessments on a variety of care and service issues. The Los Angeles EMA alone conducts over 30 needs assessments on a variety of HIV/AIDS care and service issues. We knew from the outset that it would be extremely difficult to bring together in one succinct summary document the key findings and concerns of all of these providers and plans.

To respond to this challenge, the State Office of AIDS assumed the role of lead agency and convened - in mid-1997 - a group of volunteers to design an initial framework for the overall development of an SCSN. The group was composed of five members of the HIV Comprehensive Care Working Group, who - although not officially representing them - consisted of people living with HIV (PLWH) and representatives of various Ryan White CARE Act grantee agencies. Because the intent of the SCSN is to assure better coordination among CARE Act grantees, the committee worked to design a process that would be locally driven (with local grantees working together) and would feed into an overall statewide process.

The process to gather input to the SCSN consisted of six key elements:

1. **Creation of a Steering Committee to supervise and monitor the SCSN process through March 1998.** The Steering Committee met during the SCSN process to develop and distribute the final SCSN guidance to all grantees, and to give ongoing advice and input to the State Office of AIDS. The committee consisted of two representatives from Title I grantee organizations, two from Title II (state and consortium), one each from Titles III, IV, SPNS, and AETC, and two people living with HIV.

2. **Development and distribution of a common questionnaire to individual California counties on SCSN-related topics.** Through this questionnaire (see Appendix 4), counties and groups of counties had the opportunity to develop their own local input process for the SCSN, and to convene representative groups of individuals - including people living with HIV - to develop recommendations and statements for the SCSN. Responding counties were responsible for gathering input from all CARE Act grantees operating in their region, and for compiling and summarizing local and regional needs assessments across populations and service categories. Several individual agencies also provided responses to the questionnaire, based largely on special needs of their own service populations.

3. **Sponsorship of three forums for people living with HIV in California.** Three full-day forums were held to elicit input directly from persons living HIV, across the broadest possible spectrum of ethnic, age, gender, and regional characteristics. With input from PLWH members of the HIV Comprehensive Care Working Group, the State invited 54 individuals to participate in these forums, which consisted of a People Living With HIV Forum in San Francisco on November 21, 1997; a Women Living With HIV Forum in Oakland on December

11, 1997; and a People of Color Living With HIV Forum in Los Angeles on December 16, 1997. The input from the meetings was transcribed from tape recordings.

4. **A series of meetings among representatives of State programs, agencies, and planning groups involved in HIV services and service planning.** The Office of AIDS coordinated meetings among representatives of relevant State agencies and programs such as Tuberculosis Control, Corrections, Maternal and Child Health, Office of Women's Health, Employment Development Department and Drug and Alcohol Programs, as well as program managers within the Office of AIDS, to discuss existing and emerging trends in the epidemic, and to propose recommendations for future action and goals. The State also conducted a comprehensive review of prior needs assessments and needs survey documents previously prepared by the State Office of AIDS, and by other relevant departments at the state level.

5. **Appointment of a contracted technical writer to compile the three elements above into a draft SCSN document.** A technical writer was appointed through a statewide RFP process in late 1997, and a first draft of the SCSN was prepared and distributed to all participants in the process in late January 1998.

6. **A series of teleconferences to discuss the SCSN draft, and to hear feedback from CARE Act grantees statewide.** Through a series of four hour-long teleconferences - held on February 6, 9, and 13, 1998 - CARE Act grantees were given the opportunity to respond to the first draft, and to discuss modifications and refinements of the SCSN. Agencies and institutions also had the opportunity to respond in writing if they preferred. These comments and responses were incorporated into the present re-edited, final version of the California SCSN.

The following document, while brief, is thus an attempt to summarize - across all regions, groups, and providers in the state - the key trends, goals, and possible future actions related to HIV/AIDS service and care in California. Although by no means all-inclusive, the document does represent findings compiled through a broad process that encouraged agencies and individuals to come together within their individual counties regardless of service category or service population lines. In turn, the SCSN became a unique opportunity to compile and synthesize the overarching trends, concerns, and cross-cutting issues in the field of HIV/AIDS service and care in this diverse and multi-faceted state.

C. Overview of California and its HIV/AIDS Epidemic

The state of California - diverse, complex, and geographically vast - is by far the most populous state in the nation, with a July 1990 Census population of 32.9 million persons. The state has 65% more residents than the country's second most populous state, New York, and experienced an expansion in total population of nearly 26% between 1980 and 1990 alone. Three of the five most populous counties in the United States, as well as the largest county geographically in the continuous United States, are in California, and according to the 1990 U.S. Census, 10 of the 14 fastest growing cities in the U.S. between 1980 and 1990 were California cities. Just under 12% of all Americans, or nearly one out of every eight U.S. residents, call California home.

The 58 counties that make up California cover a total land area of over 156 million square miles, encompassing deserts, mountains, forests, coastline, and farmlands, and including urban, rural, and semi-rural population centers of all sizes and characteristics. Four California cities - Los Angeles, San Diego, San Jose, and San Francisco - are among America's largest 14 cities. The state's two hardest-hit cities in terms of total AIDS incidence and caseload - Los Angeles and San Francisco - alone include a combined population of over 4.2 million persons, or nearly 15% of the state's total population.

RACE & ETHNICITY IN CALIFORNIA: FINDINGS OF THE 1990 CENSUS

Ethnic Group	# of Residents	% of Population
African-American	2,226,867	7.44%
Asian/Pacific Islander	2,711,989	9.06%
Latino/Latina	7,949,606	26.55%
Native American	183,852	0.61%
Other	56,092	0.19%
White	16,812,674	56.15%
Total	**29,941,080**	**100%**

The state of California is also notable as a center of ethnic and cultural diversity within the United States. People of color will constitute a majority of the state's population by the year 2000, and foreign-born individuals already make up just under 25% of the state's overall population. Twenty-nine percent of Californians speak a language other than English at home, and 600,000 officially recognized refugees, originating from all corners of the world, make their home in California. In addition, three of the five most racially diverse counties in the U.S. - San Francisco, Los Angeles, and Alameda Counties - are located in California.

In many ways the AIDS epidemic in California is reflective of the demographic composition of the state itself, in that it is large, ethnically and culturally diverse, complex, and dispersed throughout a geographically vast region. As of December 31, 1997, a cumulative total of 104,638 AIDS cases had been reported in California, and of these, 66,263 had died, for an overall case fatality rate of 63%. Figure 1 displays AIDS cases and deaths by half-year of diagnosis. **California currently accounts for approximately 17% of the cumulative AIDS cases reported in the United States.**

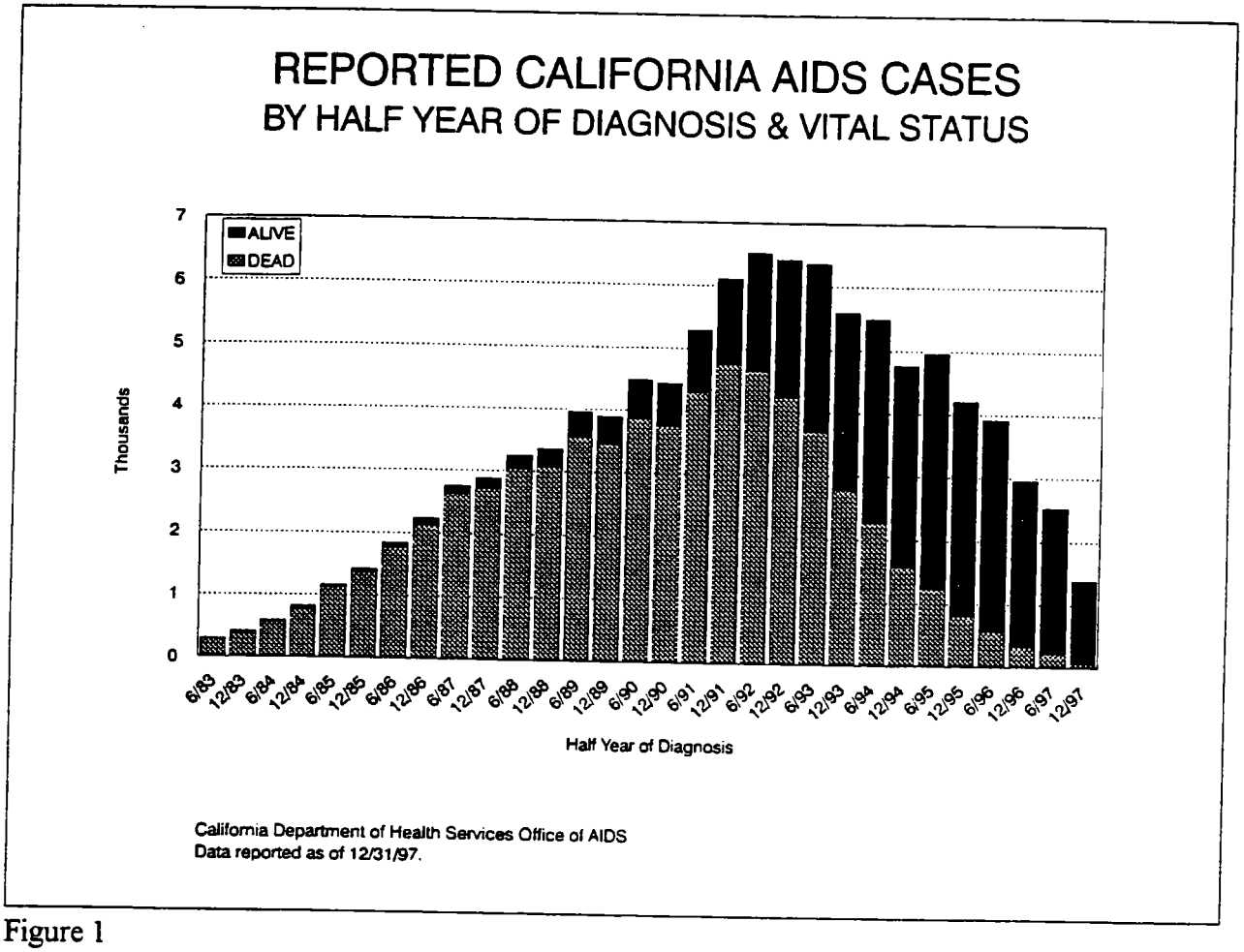


Figure 1

In 1996, a number of new drugs became available to treat HIV-infected individuals both before and after an AIDS diagnosis. These drugs are almost certainly a major reason for the drop of over one-third in the number of new cases diagnosed since 1996 and a 60% drop in the number of deaths attributed to AIDS between the first half of 1996 and the first half of 1997. These changes may mean that the use of AIDS case data to analyze trends in the epidemic has become less accurate, and therefore less useful. The latest Registry data reveal the following trends:

- Whites accounted for 63.3% of cases reported through the end of 1996 but only 49.0% of cases reported in 1997. African Americans accounted for 16.1% of pre-1997 cases, compared with 20.8% of 1997 cases. Cases among Latinas/os also increased, from 18.1% of pre-1997 cases to 26.9% of 1997 cases.

- The percentage of reported AIDS cases among men who have sex with men (MSM) continues to decline, but this remains the predominant risk group in California. Through the end of 1996, 73.0% of reported cases were among MSM; however, among cases reported in 1997, only 62.8% are among MSM.

- The number of new cases reported among adult women is increasing. Of the cumulative AIDS cases among adult men, 16.7% were reported between January 1996 and December 31, 1997. During the same time period, 30.1% of the cumulative AIDS cases among adult women were reported.

- Heterosexual transmission accounted for only 3.6% of cases reported before 1997, but increased to 8.4% of cases reported in 1997.

- Since January 1996, only California's four smallest counties have not reported any new AIDS cases, including Alpine County which has never reported a case. Among large counties, San Francisco County experienced the greatest decline in percentage of new cases, accounting for 21.6% of all cases reported before 1997, but only 16.4% of cases reported in 1997. Likewise, the percentage of new cases reported from Los Angeles County declined during the same period, from 31.8% before 1997 to 30.1% in 1997. The percentage of cases reported from the rest of the state increased from 46.6% before 1997 to 53.5% in 1997. Approximately 90% of all cases of AIDS in California continue to originate in urban areas.

- Heterosexual injection drug users accounted for 9.6% of all cases reported before 1997 but constituted 13.3% of cases reported in 1997. Cases among men who have sex with men and use injection drugs showed a similar increase, accounting for 8.4% of cases reported before 1997 but 9.8% of cases reported in 1997.

D. Findings, Part I: Current Issues, Trends, and Needs

Introduction

The size and diversity of the state of California presents unique challenges to the planners of HIV care and services. Programs must be designed to serve exceptionally varied groups and communities with specifically targeted programs, while reaching large populations in urban and suburban areas, and far flung populations in rural and frontier communities. Programs must overcome divisions brought about by geographic boundaries or distance and by health jurisdictions, while simultaneously forging collaborations so large that consensus-building often occupies a great deal of provider time. In addition, programs must serve communities and groups which have differing needs, while linking and integrating these services among widely different providers. The high level of poverty in which many Californians with HIV live further complicates the struggle to deliver effective, comprehensive services.

Yet if the culture and environment of California make it a challenging site in which to forge and implement an effective system of services, then the range, depth, and complexity of its populations also make it an ideal site in which to develop creative and effective service models that respond to a diverse human community. If HIV has brought struggle and tragedy to California, it has also brought a spirit of commitment, enterprise, and partnership to the fight to overcome it.

> ***"Things have changed dramatically for me, and for all of us in this epidemic. It's not the way it was four years ago, five years ago. And our needs have changed. But you know what? What's being offered to me hasn't changed very much....There was a time when we needed help desperately. But now most of us, on some level, can take care of ourselves if we're given the tools to do it. That's what I want. That's what my need is...I don't want someone to fix me food, I don't want someone to drive me anyplace. I want the drugs that will make me healthy enough to do those things myself. I don't want to decide if I see a doctor and when I see a doctor. I want to decide what meds I will take. I don't want somebody telling me, "No, you won't be able to adhere to this schedule, trust me, you shouldn't have protease inhibitors." I want to make those decisions for myself. The doctor is an employee, he's not your boss. The medical system is here to work in partnership with me; that's how I get my health needs met, not by telling me what to do."***
>
> ***- Mark, Person Living with HIV***

The following section briefly highlights a series of issues - some broad and some focused - which currently affect the scope and nature of HIV service delivery in California. Presented in alphabetical, rather than priority order, these categories highlight special circumstances and trends which respondents to the SCSN survey process identified as being of importance to their

work and service planning. An additional category at the end of this section includes trends and issues which will also be of special importance to California in the future. Finally, the subsequent two sections list recommendations for action.

Please note that throughout this report, the highlighting or lack of emphasis on any specific Ryan White service category does not indicate or imply that a priority is being placed on one service category over another, or that any Ryan White-funded service is in any way dispensable within the overall spectrum of CARE Act services in California. As a document summarizing existing and emerging needs and trends, this paper necessarily focuses more on those issues which present the greatest current challenges to providers, or which are currently under more focused or extensive debate throughout California's HIV/AIDS service community.

Case Management Services

- Case management services represent a significant proportion of total HIV/AIDS spending under the Ryan White CARE Act in California. During fiscal year 1995 - 96, statewide allocations for HIV/AIDS case management services under Title I were over $8.6 million and Title II case management allocations totaled nearly 4.5 million. Together, these allocations total over $13 million in funding for HIV/AIDS case management in California. Additional titles allocate funds to case management based on the service provided; however, the allocation by title is not readily available.

- While most respondents believe that case management services are, in the words of Mendocino County's SCSN document, "at the core of HIV care, orchestrating the full range of services for HIV patients," many respondents also believe there is a lack of uniform definition for what "case management services" means, or of how case management should be organized, delivered, and funded. Many clients have differing expectations about what case management services should provide, or what kinds of case management services would be most meaningful to them. In turn, these expectations and needs often differ from the ways in which providers continue to organize case management services, or from the ways in which private and public funding entities require case management services to be delivered.

- Many respondents believe there is an urgent need to expand and more clearly define precisely what is meant by the term 'case management' in regard to HIV/AIDS services in California. It is understood, however, that any such definitional change must include the possibility of different approaches to case management for different populations, and between and among various demographic groups and regions. Many local and regional efforts are now underway to assess the issue, and to prepare new recommendations and standards concerning HIV/AIDS case management content, form, and funding in California.

- Some respondents believe that Title I and Title II case management services are needlessly limited, in that they are defined mainly in terms of logistical support for medical outpatient services. In these circumstances, many providers must offer additional services for which they are not reimbursed through federal funding.

Corrections Settings and Incarcerated Individuals

- As of May 1996, California had 32 State prisons with over 139,000 inmates. The number of inmates known to be living with HIV disease/AIDS has continued to increase from monthly averages of 813 in 1992, 913 in 1993, and 1,060 in 1994. Projections developed by the California Department of Corrections estimate that there will be more than 1,400 male and female HIV-infected inmates in the state system by the year 2000. These totals do not include the many men and women living with HIV in California's federal prisons and county jails, which often lack consistent standards for HIV/AIDS care and treatment.

- There is a need for increased information and training on HIV-related drug adherence and protocols throughout the state corrections system, including programs that increase inmate's 'buy-in' and commitment to new medications. Correctional facilities should consider directly-observed therapy adherence wherever possible.

- There is a need for improved transition to public and private HIV services for recently-released incarcerated persons and for greater education and orientation regarding the various outside services available to them. In some regions, parolees are given only a limited amount of medication upon release, while in other jurisdictions, access to medications or to medical records is not provided at all. Augmented transitional case management services are needed to ensure that parolees are linked to services prior to release.

- Increased knowledge and awareness on the part of medical professionals concerning the gender-specific and specialized care needs of women is essential.

Cultural Issues in HIV/AIDS Care

- Persons living with HIV/AIDS report that a lack of culturally appropriate and culturally competent staff and a lack of awareness about cultural differences can significantly impact both their comfort level and their willingness to seek initial or follow-up services. At the same time, providers are aware that cultural competence has to do not only with racial and ethnic differences but with differences related to sexuality and transgenderism.

- Cultural barriers to receiving adequate services include patient belief systems about health and health care; religious beliefs and practices; lack of culturally appropriate materials; lack of translation services; and fear of involvement in the health care system, particularly for undocumented immigrants.

- African-Americans with HIV repeatedly request culturally sensitive services, including support groups, outreach, and medical staff. Specifically, there is a need for more African-American doctors. This population also mentions a need for more services targeting women and children; for programs that are built on assessments of community perceptions and needs; and for expanded involvement of community members in program planning and evaluation.

- Latinos/Latinas with HIV express many of the same needs that exist for African-Americans, but stress as well the need for appropriate translation and interpretation services - indicating

the added need for providers or interpreters to understand that not all Spanish speakers speak the same language. Geographic access to services is also a special need for this population, particularly in migrant worker communities.

- California's growing Asian/Pacific Islander populations face even more complex linguistic support needs, particularly in terms of the lack of multi-lingual health care professionals, and the large number of languages spoken by these groups. Due to the diversity of Asian and Pacific Islander communities, creating a single message or methodology for the Asian/Pacific Islander community as a whole presents a significant challenge.

- Particular barriers to HIV-related health care exist for Native Americans living both within and outside reservations. California has the largest population of urban-based Native Americans in the country, and culturally competent care and support services are needed in city-based facilities.

- Native Americans living on reservations are expected to seek care at an Indian Health Service or tribal facility, which may pose threats to confidentiality. Yet if these individuals seek health care outside of reservation-based health care facilities, they must apply to and qualify for other health care reimbursement support. Poor roads, long travel distances, and housing are also barriers to care for these men and women.

- Increasing restrictions on the definition of case managers limit the number of Native American case manager providers in many areas because there is an insufficient number of Native Americans who are licensed RNs or MSWs.

Drug Therapies and Emerging Combination Treatments

- The recent emergence of new combination HIV drug therapies has significantly changed the profile of HIV/AIDS care in California, creating significant impacts on client lifespan, provider services, and resource allocation. During the first six months of 1997 alone, AIDS deaths in California dropped an astounding 60% over the same period one year earlier, from 2,788 AIDS deaths in the first half of 1996 to 1,112 in the first half of 1997. This compares to a 23% drop in national AIDS deaths rates noted by the U.S. Centers for Disease Control and Prevention, and, in the mind of many, speaks to the success California has achieved in aggressively prescribing, monitoring, and refining HIV drug treatment regimens.

- The new medications, however, are expensive, with costs estimated at $15,000 to $18,000 per patient per year. In addition, the costs of assays to monitor the efficacy of antiretroviral therapies - such as polymerase chain reaction (PCR) and bDNA - are also expensive. Within the expanding context of both poverty and managed care in California, assuring access to medications for all persons with HIV remains an ongoing challenge.

- The State's AIDS Drug Assistance Program (ADAP) - aided by continuing significant contributions from California's own state budget - has thus far been able to keep pace with the demand for medications. The state program has also been successful in innovatively filling service gaps for people in poverty. This standard must be upheld, and should continually include all medications recommended in federal DHHS "Guidelines for the Use

of Antiretroviral Agents in HIV-Infected Adults and Adolescents," and subsequent revisions. Virtually all respondents stress that assuring continuing access to both existing and emerging medications will be of critical importance. The issue may become even more serious when new three, four, and five multi-drug combinations increase overall costs and put additional fiscal pressure on the state.

- It is also critical to bear in mind that while new combination therapies have meant improved health for many, other Californians have not benefited from the new medications, or have been unable to access or adhere to them. While some studies estimate that between 67% and 85% of patients will be able to tolerate combination therapies or show improvement as a result, in the San Francisco EMA, for example, at least 40% of all people with HIV "are not benefiting from protease inhibitors either because of resistance, intolerance, or inability to adhere," according to the EMA's survey response.

- In addition, despite the success of combination therapies that allow many people to successfully 'manage' their HIV condition, far too many Californians are precluded from this reality because they are perceived to be inappropriate candidates for the drugs, they need additional resources or support to fully adhere to medication regimens, they receive their first HIV test after developing full-blown AIDS, or they do not currently know their HIV status. Services such as substance abuse treatment and housing help people become candidates for the new medications, and may help them comply with complex dosage regimens.

> ***"We continue to struggle with increasing demands for educational programs on antiretroviral therapies. As new classes of drugs are approved, such as protease inhibitors and non-nucleoside reverse transcriptase inhibitors, clinicians struggle to keep abreast of side effect profiles and drug-drug interactions....Many providers who previously saw only a few HIV-infected patients are reconsidering their ability to provide high-quality care for their HIV patients. This has potential for decreasing the HIV clinician provider pool."***
>
> ***- Pacific AIDS Education and Training Center, Univ. of Calif., San Francisco***

- Many providers believe that the cumulative population of persons living with HIV/AIDS in California is expanding as a result of combination drug therapies, and that the need for basic, ongoing supportive services - such as medical care, food, and housing - will consequently also increase. Medications that extend life have also increased the need for access to specialized, one-on-one public and private benefits assistance, counseling, advocacy, job training, and vocational rehabilitation services (see Employment Development section below). Working with the HIV-infected person to prevent transmission to others becomes an imperative need as persons with HIV/AIDS are living longer, being more active, and perhaps feeling less vulnerable to HIV.

- In general, both providers and people living with HIV believe that services and service approaches will need to evolve in California in order to have a direct focus on helping clients live longer, healthier lives with HIV, rather than helping them move toward death. Yet at the same time, the availability of original short-term and 'emergency' services will remain essential to both current and new clients. This dichotomy requires an reassessment of the overall structure of the HIV service delivery system, and will most likely result in new approaches to care which involve greater collaboration and consolidation between and among HIV-specific and non-HIV-specific providers.

- In summary, it is still too early to determine how effective HIV drug treatment therapies will be over the long term, and for what segments of the population they will remain most effective. The impending release of additional combination therapies also clouds our ability to predict the impact of future treatments.

> ***"I don't want to lose my Social Security Disability, but I would like to do something, I would like to contribute to my community. But if I do, I'm gonna lose [my benefits]. And if I lose them, I'm not going to get them back. But that's a need I have, it's a real human need I have, and I want some of you to hear it, and maybe some of the money that goes for people who walk dogs* who don't need their dogs walked anymore, maybe they can figure out a program that would help me protect my disability - because I'm not cured, this is not a cure. Maybe there's some department or program that would let me go do something that would augment my income without losing my status as a disabled person. I mean, you know, on $910 a month I'm not traveling around the world all that often."***
>
> ***- Jim, Person Living with HIV***
>
> *Not CARE Act-funded

Employment Development, Placement, and Training

- The positive outcomes of new treatments encourages persons with HIV/AIDS to consider returning to work. Returning to work can have significance not only in terms of increased personal income, but in terms of enhanced self-esteem, expanded social interaction, and the satisfaction of making a concrete contribution to one's community or workplace.

- Traditional vocational rehabilitation, job training and placement, and job skills assessment, however, are complex skillsets which most AIDS service providers do not possess. Many impoverished persons with HIV have never been employed on a long-term basis, for example, and will require an especially intensive range of vocational training and placement services. It will be critical for public and private HIV service agencies and providers to develop linkages with non-HIV-specific employment assistance agencies because CARE Act funds may not be used for these activities.

- The possibility of returning to work raises a plethora of issues related to preservation of health and insurance benefits, continuation of AIDS medication support, workplace sensitivity, job discrimination, disability definition, and the need for time off. The difficulties inherent in maintaining complex medication regimes in the workplace setting further limits and complicates the issue of employment. Many individuals may justifiably fear returning work because of fears of losing health insurance and benefits and the difficulty in requalifying for services or programs such as Social Security Insurance if their health deteriorates.

- Clients need advocates to assist them with various issues including fair and equitable access to health, disability, and other forms of insurance.

- Workplace and employer education programs may be required to reduce the effects of employer discrimination against PLWH.

- Some respondents believe that vocational rehabilitation needs are highly specialized, and may not be easily accommodated in either the current HIV service delivery system or the current vocational rehabilitation/job training system without significant changes and adaptation.

HIV Case Reporting and Confidentiality

- While the issue is extremely controversial, many respondents believe that it is no longer adequate to know only how many or where individuals have received an AIDS diagnoses. Aggressive medication treatments often mean people do not progress to an AIDS diagnosis, which figures predominately in resource allocation. Many administrators, service planners, and epidemiologists believe that having increased access to information on the number and location of HIV-infected people would facilitate and improve service planning and delivery, and assure a more equitable distribution of resources.

- A consensus appears to be emerging among many providers and agencies to make HIV infection a reportable condition in California and nationwide. The inability to collect specific and timely information on the changing demographics of HIV-infected populations is seen by many as negatively impacting our ability to plan effective service delivery, to make fair and appropriate funding allocations, and to spot emerging trends early enough to effectively address them. While it will be absolutely essential to maintain and enforce client confidentiality in regard to HIV reporting, many believe that such confidentiality can now be sufficiently enforced to warrant this change.

- The mandatory disclosure of the **names** of individuals with HIV would constitute a significant problem at all levels of our service system, and is opposed at many levels of California's HIV service system. Many providers believe that in addition to the ethical and privacy issues involved, the reporting of names would definitely result in fewer persons being tested and fewer persons receiving early intervention services prior to becoming gravely ill.

- Mandatory testing of **newborns** presents similar practical and ethical problems. Testing a newborn at birth only identifies the HIV status of the mother, and several months later, the child may test negative. Mandatory testing of newboms also means that all women who give

birth in California hospitals will have their HIV status revealed, with or without their permission.

Housing

- The provision of adequate and affordable housing for persons living with HIV/AIDS remains a critical need and a major unmet service gap in California. While housing is a major problem for all persons living in poverty, these problems are magnified for persons living with HIV. In many high-cost areas of the state, affordable housing has all but vanished, while the proportion of persons with HIV living in poverty continues to expand. Homelessness creates problems not only in terms of basic health and dignity, but also radically disrupts access to services and makes continuing compliance with medication regimens virtually impossible. Yet all providers also understand that the costs of providing long-term housing assistance are high, and that collaboration among agencies will be needed to extend the availability of adequate housing for persons with HIV/AIDS in California.

- Many providers express a strong need for low-income housing that is drug and alcohol free. In the words of Mendocino County, "Housing programs where drugs and alcohol are used only lead patients with substance abuse issues to progress further away from a healthful life which is compliant with medical regimes." At the same time, some urban providers express a desire for 'higher tolerance' housing models that will not preclude individuals from receiving housing assistance simply because they have not yet overcome their substance abuse issues. There is a need to develop housing models that accommodate different client needs through a range of settings and housing models.

> ***"The need for housing impacts all aspects of someone's life, including their ability to eat, sleep, take care of themselves, and receive other services. When clients live in tentative housing situations or are homeless, the amount of services they need increases tremendously, placing a strong burden on the entire HIV service system."***
>
> ***- Contra Costa County SCSN Response***

Managed Care Issues

- As the costs of health care accelerate in the United States, and as competition among health care providers increases, health care organizations seek to provide higher-quality services for less money, and to accumulate larger patient loads. Managed care, which couples the provision of health care with the payment system of health care, has grown enormously. A managed care program, frequently a Health Maintenance Organization (HMO), manages all aspects of a patient's care, and including services. California has been in the forefront of the move to managed care nationally; most commercially insured working individuals in the state are now enrolled in some type of managed care system.

- The continued growth of both public and private managed care systems creates special challenges in relation to HIV/AIDS. While in many cases, managed care systems have increased the number of clients who receive quality medical care, some managed care clients have experienced difficulty in accessing experienced HIV specialists and combination therapies, and experienced rigidity in the application of both benefits and protocols. Organizations providing mainstream managed care primary care need to negotiate capitation rates that reflect the higher costs of providing health services to HIV/AIDS patients.

- The primary **potential** negative impacts of managed care on persons with HIV include: lack of access to specialists; clinical decisions based on cost savings; providers disallowed from functioning as the patient's advocate; limited drug formularies based on price; lack of quality assurance specific to HIV clinical indicators; lack of access to case management services; avoidance of marketing to persons with HIV; and decreased access to neighborhood and community-based providers who have the experience, cultural competence, and language capacity to effectively serve affected populations.

- Medicaid is the primary safety net for providing medical care to persons with HIV and AIDS. Increasing health care costs nationally have created a precipitous increase in the Medicaid budget. To decrease the growth rate, and to continue the trend towards defunding of federal entitlement programs, Congress is considering restructuring the Medicaid program and reducing its funding. Across the country, states have implemented Medicaid managed care plans to control costs. The California Medicaid (Medi-Cal) program instituted three types of managed care plans to provide medical services to Medi-Cal beneficiaries. The County Organized Health Systems, organized in five counties, include all Medi-Cal beneficiaries in the managed care program. The Geographic Managed Care was established in Sacramento and San Diego counties, where Managed Care Plans (MCPs) contract with the Department of Health Services to provide medical services to AFDC recipients on a mandatory basis and to the aged, blind and disabled on a voluntary basis. The Two-Plan Model was developed in 12 counties. This model establishes one locally developed MCP and one commercial MCP to provide care on a per member/per month fee basis. AFDC beneficiaries are mandated to enroll, and the aged, blind and disabled may voluntarily enroll.

currently under revision

- ~~Medicaid capitation rates were negotiated by some MCPs providing services to HIV-positive members in California; however, these rates did not cover all costs and Medi-Cal Managed Care instituted a program to reimburse providers for the additional costs of treatment and medications. A capitated rate for all Medi-Cal programs is under development and expected to be in place by July 1998.~~

Mental Health Services

- In addition to the psychosocial burdens common to other terminal diseases, such as adjusting to diagnosis, preparing for loss and bereavement, and providing necessary care and shifting family roles, persons with HIV and their families frequently need help addressing fears of infection, to accept the individual's sexual orientation or drug use, and to overcome the stigma and discrimination associated with HIV/AIDS. All of these can lead to additional conflict, stress, and need for reconciliation.

the stigma and discrimination associated with HIV/AIDS. All of these can lead to additional conflict, stress, and need for reconciliation.

- A need also exists for expanded availability of psychiatrists and other mental health professionals who are fluent in languages other than English, and who can be accessed within primary medical care settings wherever possible.

Multiple-Diagnosed Populations

- Many providers believe that the number of persons living with a so-called 'triple diagnosis' - that is, infected with HIV and living with diagnosed substance abuse and mental health conditions - is increasing in California. Within these populations, the range of needs and the difficulty of delivering adequate services is greatly magnified, as are issues related to medication eligibility and compliance.

- Individuals with serious psychiatric and substance abuse problems require specialized, complex, and coordinated interventions, and a greater level of interdisciplinary service integration than we have thus far been able to muster.

- Unfortunately, the complexity of the multiply diagnosed still leads some providers to necessarily 'write-off' those clients because of the intricacy and expense involved in their care and treatment.

> ***"Effectively treating people who have serious psychiatric and substance abuse problems takes coordination and expertise heretofore not required by community HIV service providers. Services such as case management for detox patients, placement for these clients, and emergency psychiatric services are expensive and historically have high rates of recidivism. ...Other specialized services for severely impaired and indigent clients are intensive, expensive, and will require tremendous coordination efforts between specialists."***
>
> ***- San Francisco EMA SCSN Response***

Oral Health Services

- Providers state that ascertaining and meeting the oral health needs of HIV/AIDS-affected populations should be a priority within the HIV treatment continuum. HIV-positive individuals often manifest oral symptoms of infection first, and the oral health practitioner can play a critical role in the early identification and management of HIV disease. Many HIV/AIDS patients are also medically compromised and are at greater risk for oral lesions and for both typical and severe forms of periodontal disease, increasing the need for more complex and costly treatment. Yet dental care remains a consistently under-met client need in many areas of the state.

- Some providers believe that with the potential for increased numbers of HIV-positive asymptomatic or moderately immunocompromised patients resulting from new drug therapies, dental providers will need to shift much of their emphasis back toward routine maintenance and preventive dental services, and away from more advanced dental procedures, providing more long-term preventive dental regimens than short-term palliative treatment.

Poverty as a Public Health Issue

- Poverty is an overarching issue which affects every aspect of service delivery and planning. The majority of persons with HIV in California are living in poverty, and many respondents directly or indirectly allude to the fact that they are increasingly seeing poverty as an issue which underlies much of what providers are attempting to address in providing basic HIV/AIDS support and services.

- While poverty is emerging as inextricably linked to HIV/AIDS service and care, poverty itself is not an issue that the existing AIDS service system can fix. Providers are finding innovative ways to address poverty issues within the context of HIV/AIDS care and service, and within the context of client empowerment and education.

> ***"As the demographics of the epidemic shift to include larger numbers of women (including single mothers), people of color, and low-income individuals, the strategies developed to met these needs must also change. In many communities, an inherent distrust of the established medical system keeps many people from learning about HIV and receiving services; in other situations, clients have grown tired of an educational model based on incomprehensible medical lectures. HIV is often only one of a myriad of issue clients face. To take care of the HIV, the other needs must be addressed - including unemployment and other issues related to poverty."***
>
> ***- Contra Costa County SCSN Response***

Primary Medical Care

- Virtually all cross-cutting needs assessments in California rank primary medical care as either the most or one of the most critical priority service areas for persons living with HIV and AIDS. Primary medical care services seek to monitor and maintain the client's overall physical health, and to link the patient to emerging treatments, therapies, and health care approaches.

- Comprehensive primary care services must be accessible and affordable for all persons living with HIV/AIDS in California, regardless of changes in the nature and scope of the HIV-affected population, or of medical diagnosis and treatment techniques now and in the future.

Rural Service Issues

- According to the Office of Statewide Health Planning and Development, approximately six million people, representing about 20% of the state's population, live in rural areas in California. The Office of AIDS reports estimate seroprevalence of HIV in rural counties between 135 and 187 to 100,000. This equates to between 12,500 and 17,300 HIV-infected individuals living in rural areas in California.

- Key service issues in rural areas continue to include lack of transportation; lack of skilled service providers; and a shortage of local doctors, nurses, and other health care professionals skilled in the provision of HIV services. Many rural providers have proven resistant to seeing Medi-Cal patients, and some continue to refuse care to patients with HIV, or have no interest in taking patients with HIV into their private practices. The growing numbers of uninsured patients in rural areas presents significant barriers to care.

- Some providers report that many "rural" clients seek services in larger metropolitan areas of the state. Others report an increase in urban clients returning to rural counties to live with family or for an increased quality of life. Due to funding allocations based on AIDS diagnosis, this migration to rural areas can quickly strain budgets that may not reflect the actual number of local HIV-positive residents.

> ***"The needs of rural areas are distinct from urban areas because of geographic isolation and the fact that rural areas are often medically underserved. This in itself limits access to basic primary medical and oral health care, mental health services, and lab and pharmacy services....Patients must sometimes travel for hours, or through mountainous areas, to reach medical care, and public transportation often does not serve them because their living place is too remote. Further compounding the problem is the fact that in rural areas patients often must obtain their medical, dental, mental health care, and social services at different locations, which results in several trips instead of one."***
>
> ***- Mendocino County SCSN Response***

Substance Abuse Treatment and Diagnosis

- The percentage of clients infected with HIV as a direct or indirect result of intravenous drug use is increasing in California. In Contra Costa County, for example, approximately 36% of consumers identify injection drug use as a probable mode of infection.

- Substance abuse issues have a tremendous impact on the ability of persons with HIV to access appropriate HIV services and effectively adhere to combination therapies. In the words of the Contra Costa County HIV/AIDS Consortium response, "Clients who use/abuse substances often lead unstable lives and are frequently poor, and often require more extensive emergency services and provider time. Often these individuals cannot utilize the new drug treatments, and, because of the impact of substances, are relatively sicker at the time they enter the system. Substance use also inhibits these clients' ability to follow care plans and use good judgment, often requiring more intensive case management services than clients who are clean and sober." In addition, patients who abuse drugs are also more likely to engage in unprotected sexual behavior which may place others at risk for being infected with HIV.

- There is an urgent and continuing need for more HIV-specific substance abuse programs and for expanded drug and alcohol treatment slots of all kinds throughout the state, including supportive and transitional housing for persons leaving drug treatment programs. The integration of substance abuse programs must be expanded, and the current state of fragmentation in these services reduced.

- Individuals who may have identified drug and alcohol treatment needs may refrain from accessing services due to the penalties accessing basic services in light of welfare and benefits reform. Individuals who have been previously diagnosed with drug and alcohol conditions are now unable to access some essential services in California.

> ***"Providers will need to change the way they work with substance abuse providers to help them accommodate the needs of HIV infected substance abusers. [The] system needs to provide trainings to service providers around working with the substance abusing population more effectively. The inability to take these steps means that clients will continue to not receive the help they need, will continue to have larger medical and social problems, and require more assistance from providers in the long run."***
>
> ***- Contra Costa County SCSN Response***

- In the case of substance users, clients may also refrain from safer behavior because they are afraid that disclosure of HIV status will lead members of their peer group to make assumptions about how they were infected with HIV.

Transportation Services

- Transportation services for persons with HIV/AIDS remains a critical gap throughout California. Transportation is vital not only for accessing medical and psychosocial services, but in emergency situations as well.

- Clients with tuberculosis (TB) have multiple service needs, many of them specialized, including housing, transportation, and support to ensure adherence with both HIV and TB medications. Health care providers require specialized training to ensure that they properly access clients' communicable status and avoid placing infectious TB clients with HIV-positive TB and non-TB clients.

- The state is seeing a larger number of intravenous drug-using (IDU) clients with TB, and approximately 60% of California TB clients originate from other countries. Welfare and Immigration Reform movements may be having a particularly adverse impact on HIV-positive immigrants with TB.

Welfare and Immigration Reform Policy Issues

- Changes in federal law brought about significant reforms in welfare and immigration policy in 1996. These new federal laws require states to ensure that undocumented immigrants do not receive public assistance except in emergency situations. The implementation of welfare reform legislation may affect the 38% of legal immigrants residing in the United States who receive benefits in California. Welfare reform legislation will also impose new financial and service burdens on local systems of care.

- Welfare reform enabling legislation was passed by the California Legislature and signed by the Governor in September 1997. Most provisions will become effective January 1, 1998. Major features are presented in Appendix 2. It is likely that these changes will affect many persons living with HIV, particulary immigrants and families with children.

- Welfare reform is expected to lead to a loss of SSI benefits for some HIV-infected individuals if they are unable to return to work. Those persons unable to obtain work may be at risk for homelessness, and less able to adhere to complex medical regimens.

- Impending welfare reform programs will allow some clients to remain on Medi-Cal for a specified period of time. Other clients may lose Medi-Cal benefits, thereby shifting the cost of their care to community-based agencies and programs, some of which are funded through the CARE Act.

- While it is too early to see direct effects, many providers believe that clients will be adversely affected by welfare and immigration reform. As noted by the Contra Costa County HIV/AIDS Consortium response, "HIV-positive women who receive AFDC/TANF may be subject to new work requirements and/or loss of benefits and food stamps; men and women convicted of a felony will also lose benefits; and immigrants who are HIV-positive and have lost access to public assistance will be severely impacted....This population is [also] more likely to be sicker and to require greater amounts of case management time, substance abuse assistance, and general emergency assistance." The extent to which this is likely to occur is unknown, based on a person's ability to obtain work for the first time, or return to work.

- Immigration reform policies will make it difficult for some clients to maintain Medi-Cal benefits while they work. In addition, undocumented persons do not have access to Medi-Cal, and

work requirements and/or loss of benefits and food stamps; men and women convicted of a felony will also lose benefits; and immigrants who are HIV-positive and have lost access to public assistance will be severely impacted....This population is [also] more likely to be sicker and to require greater amounts of case management time, substance abuse assistance, and general emergency assistance." The extent to which this is likely to occur is unknown, based on a person's ability to obtain work for the first time, or return to work.

- Immigration reform policies will make it difficult for some clients to maintain Medi-Cal benefits while they work. In addition, undocumented persons do not have access to Medi-Cal, and are currently entirely dependent on CARE Act funding. Future restructuring of CARE Act funding must take into account the demands of undocumented persons on medical and other HIV services.

Women's Health

- Respondents report that women have pressing needs for drug-free, safe, affordable housing; food; and financial assistance. However, women with children may need a higher level of services than many other groups, particularly because women are frequently the primary, if not the only caregiver for their children. Women often express a need for accessible and affordable child care, as well as appropriate family legal services for guardianship and adoption services.

- Some respondents believe that too many women are being forced to "fit" into a system originally designed to serve gay and bisexual men. Many women with HIV report a lack of knowledge and experience among medical professionals about the effects of HIV on women, lack of specialized care, insensitivity to their needs, and a lack of respect for their concerns and their confidentiality.

- Women face many additional problems, including difficulties obtaining SSI and Medi-Cal benefits; lack of adequate respite care services; and lack of specialized "family" services within HIV service agencies, such as on-site child care or family menus at food bank service programs. The seamlessness and comprehensiveness of women-related HIV services must also be expanded and enhanced on a statewide basis.

- Women with HIV also need to access affordable obstetrical and gynecological care. For example, one of the primary indicators of HIV infection among women, yeast infections, often either goes undetected or is dealt with superficially.

- There is a lack of research around women and medications. Many providers believe that women may have different drug reactions and drug-related complications than men and that these differences must be more closely investigated and explored to improve the efficacy of prescribed medication for women.

- Rural services for women are particularly inadequate and lack comprehensiveness.

- Impending welfare reform initiatives have the potential to seriously impact women with HIV in California. Once they are off of welfare, many women will no longer have access to health care, while the jobs these women do acquire will often not offer adequate health care.

- Appropriate prenatal care is needed at all levels, particularly to prevent perinatal transmission of HIV, and to prevent subsequent after-birth health problems when HIV is not diagnosed through voluntary testing.

Young People and Adolescents

- It is estimated that one in four new HIV infections in the United States occurs among persons 13 - 21 years of age. Youth are not accessing counseling and HIV antibody testing or care and treatment in numbers which correspond to their reported infection rates. In addition to the more widely acknowledged HIV risk factors of sexual intercourse and drug use, the disassociation between behavior and consequences, lack of family support, and low self-esteem are characteristics of HIV-positive and high-risk youth.

> ***"HIV-positive youth must have access to youth-centered, culturally appropriate, coordinated, community-based, confidential, and affordable primary medical care and support services. HIV services must be linked to other support services, such as housing, food, vocational training, mental health counseling, etc. Systems of care must respond to the needs of specific sub-groups of youth, including young men who have sex with men and homeless and runaway youth."***
>
> ***- Health Initiatives for Youth, San Francisco***

- Many youth-focused providers agree that there is a clear need for more and better HIV/AIDS services that are directed specifically to youth, including primary medical care, mental health, and substance abuse services, and social services such as mentoring and vocational training programs. Special attention must be paid to the issues of engaging youth in care and increasing medication adherence.

- Service providers need specialized training in working with youthful populations and at-risk youth, and young people must be involved in the planning, implementation, and evaluation of services they receive.

Additional Trends and Areas of Concern

- Many respondents note that the most reliable current predictors of unmet need for people living with HIV are low socioeconomic status, dependent family members, and a history of injection drug use.

- Individuals who speak a primary language other than English often have a significant need for on-site translation services at HIV/AIDS service agencies.

- Vision care and ophthalmology are essential services that are too often left uncovered by existing HIV service configurations.

- Some regions believe that competition among EMAs for limited federal funding acts as a barrier to increased collaboration among regions and systems.

- In San Diego County and other California regions, the California/Mexico border presents unique health issues. There are many people who cross the border to seek treatments, and many residents who defer care and treatment because of concerns regarding residency and citizenship. Standardized needs assessment techniques do not capture issues related to the border.

- Enhanced client education is becoming an increasing consumer need in California, especially in terms of expanding client empowerment and self-care capacity in light of new medications. This includes expanding information on medical adherence, client nutrition, and accessing services.

- African-Americans continue to be under-represented in terms of their participation in some regional systems of HIV care.

- Some agencies complain of "over-bureaucratization" at the funder level, which often either requires agencies to spend undue amounts of time on reporting and recordkeeping which could otherwise be spent on client services, or which shifts the burden of coordination onto community-based organizations.

- Many providers are worried about the reduction or elimination of Ryan White CARE Act funding when current authority expires in 2001. Many, if not most local service providers rely heavily or primarily on CARE Act funds and have built service patterns around program regulations.

- Data collection among smaller or emerging HIV service providers poses an ongoing challenge. The complexity of software and reporting requirements often exceed the capacity of untrained or volunteer staff, and extensive training and technical assistance - as well as additional financial support - is often needed to make complex evaluation packages effective at the agency level.

- Many providers and agencies express an opinion that financial resources for HIV services are, in the words of the Contra Costa County HIV/AIDS Consortium, "becoming scarce, in part because of the inability to base funding and planning on HIV prevalence rates, and the fact that AIDS is increasingly being perceived as a chronic disease rather than an immediate emergency."

- Many providers believe it is important to preserve local planning to assure that localities and agencies have maximum flexibility in designing services to meet the needs of their specific service populations.

- Staff and volunteer burnout is becoming a significant factor complicating delivery of services, in addition to reduced funding and lessened public interest in the AIDS issue.

- Patients with HIV disease who are responsible for taking care of children typically neglect their own health to care for their children. Families and parents, whether they are HIV infected themselves or parenting a child who is HIV-positive, need access to affordable child care and respite care.

- Some respondents express a desire to access printed and audiovisual materials on new drug therapies that do **not** promote and/or focus on the pharmaceutical companies and their specific products, but that empower clients and encourage participation in care from a client-centered, rather than product-centered standpoint.

- The HIV care system in California is still not seamless - gaps in transitional services continue to exist, and it can still be difficult for clients to transition between services.

- The fact that migration within the state is common following an AIDS diagnosis means that the location in which an individual received an AIDS diagnosed is not indicative of where they currently live or receive services. This can in turn affect the planning and delivery of services and affects funds and how they are allocated.

> ***"The epidemic and the standard of care are both in a state of dynamic flux. Shifting emphasis in new infection modes of transmission have increased the numbers of women, children, and injection drug users being served, and an increasing proportion of HIV-infected among the homeless, and multi-diagnosed, continue to receive a broad range of services. The potential to achieve dramatically reduced viral loads with access to complex drug regimens has increased the challenges of primary care providers to advance the standard of care and develop new mechanisms to support adherence."***
>
> ***- California Conference of Local AIDS Directors***

- The so-called "survival needs" - food, clothing, and shelter - remain of primary importance, especially in the state's most impoverished communities and regions.

- California clients have expressed a need for expanded and enhanced financial planning, management, and budgeting support and education statewide.

- Some respondents worry that states with effective ADAP and medications access programs - rather than being lauded for their efforts and accomplishments - may be 'penalized' by reduced funding because residents with HIV are not progressing as rapidly to an AIDS diagnosis as in other states, which in turn makes statewide AIDS case data decline, affecting resource allocation.

- Migration into California following an HIV or AIDS diagnosis because of the comprehensiveness of HIV services may increase the state's population of unreported clients in need of services.

- Individuals with pre-existing disabilities other than HIV/AIDS face special barriers to access. For the deaf, for example, full access to the entire range of services is impossible in many parts of the state. Obtaining interpreter services is difficult, even for medical appointments, and interpreting services may be unavailable for psycho-social appointments. Friends or family members brought along to interpret at service appointments may not be fluent in sign language, or dispassionate enough to interpret without interjecting their own opinions or distorting the messages.

- Many local and regional communications systems could benefit from significant upgrading and expansion as a way to enhance interagency communication, reporting, and planning. Identifying additional resources for strategic technological investment by agencies and providers, and enhancing planning to move toward 'paperless' recordkeeping systems, could help increase the quality and effectiveness of client service delivery and resource allocation.

E. Findings, Part II: Service Goals

The following is a **non-prioritized** series of broad proposed goals for HIV/AIDS services and care in California over the coming months and years, based on findings that have a broad consensus among HIV providers and persons living with HIV throughout the state:

Overarching Care and Service Goals:

- Ensure that all persons living with HIV in California receive all services necessary to sustain and support their health and quality of life, regardless of income or ability to pay, and across all stages of illness.

- Ensure that HIV/AIDS services in California are delivered in an equitable, client-centered manner, and that services respond sensitively and appropriately to client age, gender, cultural group, primary language, sexual orientation, income, region of residence, family status, health status, incarceration status, and legal residency status.

- Ensure and protect the confidentiality of all persons with HIV and AIDS in California, particularly as reporting requirements related to HIV and AIDS diagnosis may change in the future.

- Expand the participation of persons living with HIV at all levels of HIV/AIDS planning, needs assessment, systems design, service implementation, and evaluation in California, and enhance opportunities and incentives for this participation. Ensure the participation of members of specific populations - such as women, young people, and people of color - in the development of services specifically geared to these populations.

- Maintain and enhance an effective system of care for men and women living with HIV/AIDS by sustaining and strengthening California's community-based system of HIV/AIDS care in spite of the many changes now confronting the U.S. health and social service system. This goal is vital not only because of the quality and scope of support that the system offers to people with HIV in California, but because the system provides a model for the provision of community-based care in other health and social service areas. To assure equitable and quality care for all needy Californians, efforts must be made to raise the response to other social issues and diseases **up** to level of HIV/AIDS, and not **down** to a lower common denominator in which none receive the proper levels of community-based care, support, advocacy, and assistance that they need and deserve.

- Support the continuation of locally-based HIV/AIDS planning with the widest possible scope of HRSA-eligible service categories available to local jurisdictions and agencies. Each HRSA category fills a valid unmet need somewhere in the state's service delivery system and should be maintained in the continuum of care for the state.

Case Management:

- Improve the quality of service access and coordination for persons living with HIV/AIDS by increasing the professionalism, relevance, comprehensiveness, and client sensitivity of case management services at all levels of care, and by expanding efforts to create and support integrated case management systems and definitions throughout California. This includes reorienting case management in relation to new drug therapies; expanding case manager training and education; recruiting greater numbers of self-disclosing HIV-positive case managers; reducing unreasonable client caseloads; and facilitating greater integration and consolidation of regional case management systems among social and medical service agencies.

Corrections Settings and Incarcerated Individuals:

- Expand the participation of care providers from the corrections system in HIV planning bodies in California, and ensure full access to combination therapies and compliance support in correctional settings.

Drug Therapies and Emerging Combination Treatments:

- Ensure the universal availability and subsidization of all appropriate new and existing medications and drug treatment combinations for all eligible persons with HIV who wish to receive them.

- Expand the number of candidates for combination therapy through relevant services such as substance abuse treatment, housing, transportation, and case finding, and provide services to support patient adherence at all levels.

- Ensure continuing professional competence in prescribing and monitoring medications for persons living with HIV/AIDS and in supporting patient adherence through mandatory continuing education, professional training, and the development and dissemination of continually updated clinical standards.

Housing Services:

- Ensure that persons with HIV/AIDS - including families affected by HIV - are able to access a comprehensive continuum of housing services and resources, including emergency shelter, transitional housing, housing/rental subsidies, foster homes, congregate living facilities, skilled nursing facilities, board and care facilities, transitional housing for parolees and others released from prisons and detention facilities, and housing for people with multiple diagnoses. Ensure that HIV/AIDS housing is available in the least restrictive form desired by each individual. Develop strategies and technical assistance resources to help communities access additional housing resources for persons with HIV/AIDS. Encourage and provide incentives for local jurisdictions to utilize Community Development Block Grant funding, HUD funding, and other housing funds as sources for building or converting low-income housing specifically for persons with HIV/AIDS.

Managed Care:

- As private managed care providers are given more responsibility for caring for Medicaid beneficiaries, and as the prevalence of managed care systems in California expands, ensure that people with HIV/AIDS who are enrolled in these systems have access to the leading standards of care for HIV disease. Require that managed care organizations provide geographically accessible, specialized, and qualified HIV/AIDS services and providers for all persons with HIV. Require that a clearly-understood and easily accessible consumer grievance system is in place in all managed care programs. Adjust managed care capitation rates or create 'carve-outs' where needed to reflect the full range and frequently higher costs of service provision for persons with HIV/AIDS. Ensure an adequate Medi-Cal capitation rate that includes drug treatment, outpatient medical and dental care, social services, and risk of inpatient care.

Multiple-Diagnosed Populations:

- Ensure the development and implementation of a comprehensive system for addressing the needs of multiple-diagnosed populations in California - particularly individuals affected by HIV and by mental health and substance addiction. Assure that the complex needs of these individuals are addressed so that they do not 'slip through the cracks' as health systems focus more closely on cost-efficiency and cost savings in light of managed care. Explore the possibility of integrated funding to support these services within a unified framework.

Primary Medical Care:

- Ensure that comprehensive primary medical care services are accessible and affordable for all persons living with HIV/AIDS in California, regardless of changes in the nature and scope of the HIV-affected population, or of changes in medical diagnosis and treatment techniques now or in the future.

Poverty as a Public Health Issue:

- Address the fact that a growing percentage of HIV-related client needs and problems are rooted in poverty by developing effective methods to jointly address poverty and HIV issues in California. Increase opportunities to form and develop partnerships between HIV providers and poverty-related community groups and residents in order to expand and deliver services for both populations.

Research and Clinical Trials

- Include the broadest possible cross-section of populations affected by HIV/AIDS - including minority populations, adolescents and young adults, women, and injection drug users - in government-sponsored clinical trials programs, and expand the opportunities for persons with HIV from all economic, geographic, and cultural backgrounds to participate in clinical trials research. Support research on complementary and alternative therapies as an

important strategy for exploring potentially promising new treatments for HIV disease. Continue and expand support for research into models of service delivery, models of evaluating effectiveness and efficiency in care delivery, client adherence to care appointments and therapeutic regimens, and the importance of cultural responsiveness in improving client adherence

Rural Issues:

- Address continuing HIV/AIDS service deficiencies and barriers in rural areas, including lack of transportation, lack of skilled service providers, and a shortage of doctors, nurses, and health care professionals qualified and trained in HIV care.

Service Integration and Coordination:

- Enhance the quality, scope, and coordination of care for persons living with HIV/AIDS in California by increasing the ability of providers to plan and develop collaborative, multi-disciplinary approaches to HIV service and care, especially in light of the changing, complex needs of those affected by the epidemic. Develop opportunities and incentives for increased interaction and service integration among providers and consumers, CARE Act grantees, HIV/AIDS and non-HIV/AIDS-specific agencies, local and regional health jurisdictions, medical and psychosocial providers, public and private funders, private and government bodies, local and national agencies, rural and urban providers, and local and regional consortia and planning groups.

Substance Abuse Treatment and Recovery:

- Ensure the availability of substance abuse treatment programs for all persons with HIV/AIDS who wish to receive them, through a continuum of treatment options including detoxification, short-term and long-term residential care, and outpatient services. Ensure the availability of supportive services that help individuals achieve success in substance abuse, including transitional and supportive housing for individuals leaving treatment, transportation, mental health services, and job training and placement.

The Changing HIV-Affected Population:

- Examine the ways in which the existing system of HIV service and support will need to change or become more flexible to address those HIV-affected populations that are most frequently affected, including HIV-affected women and single mothers, people of color, low-income individuals and families, injection drug users, young people, people in correctional settings, and residents of rural and frontier communities.

- Examine the ways in which the HIV service system will need to evolve to confront the fact that many men and women HIV and AIDS are living longer, and are requiring a distinct set of services - including long-term housing, vocational rehabilitation, job placement, client education, insurance assistance, benefits advocacy, policy research, financial planning, and secondary prevention support - which is oriented toward helping them live long, productive, and self-sufficient lives. Address the fact that the growing perception of HIV disease as a

chronic, non-life-threatening illness is affecting both the availability of resources and the ability to sustain existing systems of care.

Tuberculosis Control:

- Recommend HIV counseling and testing for all persons with confirmed, suspected, or contact tuberculosis in California.

Women's HIV Services:

- Address the special and growing needs and problems of HIV-infected women and single mothers in California, including the need for expanded prenatal care and voluntary prenatal HIV testing to prevent perinatal transmission; increased child care and respite care resources; the potential adverse effects on women of welfare reform; the lack of competent medical advice regarding combination therapies; and the need for increased participation by women in clinical trials.

- Ensure that all California pregnant women have early access to HIV diagnosis and treatment - including the use of AZT - along with strong protections of personal confidentiality and choice. Advocate for updated prenatal guidelines for pregnant women who may be living with HIV.

F. Findings, Part III: Additional Recommendations for Future Action

The following recommendations for future actions and considerations were included in a few of the SCSN responses, but do not constitute a broad consensus. They are listed in non-priority order.

- In general, for those clients who are able to successfully 'manage' their HIV as a result of the emergence of combination therapies, the HIV/AIDS service system in California must continue to shift toward providing long-term client support for living, rather than focusing on death and dying issues.

- Assessing and addressing the needs of HIV-affected populations in rural regions must become a greater priority within California's HIV/AIDS planning processes, and solutions and approaches to rural HIV needs should become a greater collaborative issue throughout the state.

- In the process of examining, enhancing, and restructuring case management services, it will be important to bear in mind that achieving full and effective coordination of services in a given region is one of the ultimate goals of any effective case management system.

- Vocational training and employment assistance services will become an increasing priority for persons with HIV in California over the coming months and years. Cost-effective strategies and programs must be developed to help HIV providers begin to meet these needs, and to form effective collaborations with traditional, non-HIV-specific employment service providers. Any such programs must address the needs of clients to obtain or retain adequate health benefits and to support 'bridge' support during health insurance waiting periods. However, by forming partnerships to provide effective vocational training and skills enhancement services for clients, the HIV service community may be able to make a solid impact on the underlying issue of chronic poverty as it affects persons with HIV.

> ***"Given the rapidly evolving needs of people with HIV, as well as the changing public health and social service system, the challenge in Year 8 will be the design and implementation of a dynamic evaluation process to assess the interplay of existing and emerging issues....Future evaluations must incorporate outcome measures, indicators of quality of life that are more than perceptual, analyses of how effective [regions] have been in reaching under-represented groups, and how Commission functioning and effectiveness is perceived by people dependent on its competence to meet their needs."***
>
> ***- Los Angeles County EMA Response***

- Build a system of care delivery that enables localities to exercise greater flexibility in creating and adjusting services to meet changing conditions in the epidemic.

- Increase the ability of providers to plan and develop collaborative, multi-disciplinary approaches to working with people living with HIV/AIDS, especially to address the changing, complex needs of those affected by the epidemic. Increasing opportunities for providers to work as a team will increase provider knowledge of all available services, and decrease service access gaps for persons living with HIV.

- Ensure that HIV service providers are interacting with and utilizing non-HIV systems of care and support to meet the complex needs of persons living in poverty, persons with both HIV and other chronic diseases, persons seeking job training and support, persons at risk for homelessness, and others.

- Increase training for all HIV/AIDS service providers in California to help them identify and work with clients who have substance abuse issues.

- Because of the fact that combination therapies have thus far significantly impacted both the quality and length of life for many individuals - and because too many Californians do not get tested or enter the HIV care system after they have developed 'full-blown' AIDS - it is essential that the HIV service community continue to integrate outreach and service integration activities with HIV prevention and testing outreach programs in California. This should include moving toward seamless and/or on-site transitions to care for individuals receiving a diagnosis of HIV at antibody testing sites.

- Future service evaluations at the local, regional, and state level should continue to work toward the incorporation of appropriate and meaningful outcome measures and the measurement of indicators of quality of life that are more than simply perceptual. Evaluations should also analyze how effective different regions have been in reaching under-represented groups, and how persons with HIV/AIDS perceive the effectiveness of regional and state planning bodies and commissions.

- Continue to work toward the goal of a truly integrated service system with "one-stop shopping" sites wherever appropriate. This includes expanding the definition of basic, primary care to include - either through consolidation or collaboration - specialty care, dental services, mental health/psychiatric services, substance abuse services, treatment education, and case management.

- Expand access throughout the state to skilled providers that can more effectively and conveniently treat women and young adults, and work to expand the pool of skilled providers to meet the special needs of these groups. Consideration should be given to the concept of special incentives for primary care providers seeking training in HIV care for women and young adults.

- Provide state-of-the-art HIV clinical education to health care providers in both urban and rural primary care settings to ensure access to high-quality care for people living with HIV.

- Continue to work toward the development of truly comprehensive standards of care for people living with HIV/AIDS throughout the state of California.

- Adjust and change rules and laws that discourage persons who are able to earn incomes to maximize this potential without putting in jeopardy medical care and other benefits that are central to successful HIV therapy.

- The California foster care system must be examined and assessed to assure that prospective parents of HIV-infected children and newborns are fully oriented and trained concerning the needs of these populations, and that adequate planning for HIV-affected families is possible.

- More effective linkages should be developed between the US Immigration and Naturalization Service, US State Department, and Department of Health Services to address the issue of tuberculosis contagion in California.

- Expand the availability of the broadest possible range of HIV-related information and training beyond the universe of service providers funded through the California Office of AIDS.

- Create and publicize more centralized ways to access information on current and emerging HIV treatments and protocols.

- Earmark more funds for training and provider skills-building across the spectrum of HIV services.

- Broaden screening for all communicable diseases in California as part of regular comprehensive individual health assessments.

- Expand the education of California employers in regard to HIV/AIDS, including workplace treatment and anti-discrimination training, to expand the availability of suitable job placement positions for persons with HIV.

- Federal legislators should consider altering regulations and expanding CARE and HOPWA funding to provide services that can prevent the needs which these funds are designed to address. For example, the ability to support vocational training and employment assistance services could significantly help clients remain above the poverty line, in turn preventing many poverty-related problems. Similarly, the ability to use these funds to support child care services outside of licensed facilities, such as through relatives and neighbors, could more effectively help meet client needs.

- Inmate peer education programs in correctional settings need to be developed and/or expanded.

- The State of California should enhance the scope and usefulness of its HIV/AIDS Internet Web site, especially by developing linkages to other Internet sources providing up-to-date information and resources on emerging drug treatment issues.

G. Appendices

Appendix I

RESPONSES TO THE SCSN SURVEY

The following grantees, subcontractors, and other interested parties participated in or submitted responses to the SCSN questionnaire mailed by the State Office of AIDS in late 1997.

Title I Grantees:

Oakland EMA HIV Health Services Planing Council
- Alameda County Health Services
- Alameda County Housing and Community Development
- Contra Costa County AIDS Program

Los Angeles County Commission on HIV Health Services
Orange County EMA
- Orange County Housing Authority
- HIV Client Advocacy Committee
- CARE Planning Committee
- Planning Council/Consortium

Santa Clara County Health Department
- Santa Clara HIV Planning Council

Sacramento County
Riverside/San Bernardino Counties
San Diego HIV Planning Council
HIV Health Service Planning council of Marin, San Francisco and San Mateo Counties
Sonoma County Commission on AIDS/HIV

Title II Consortia:

Northern California AIDS Consortia (Butte, Sutter, Glenn, Colusa, and Yuba Counties)
- United Way of Butte and Glenn Counties

Central San Joaquin Valley HIV CARE Consortium (Fresno, Kings, Madera, Mariposa, Merced Counties)
- Fresno County Health Services

HIV Services Consortium of Santa Cruz County

Title IIIb:

Alta Med Health Services
County of Orange Health Care Agency
County of Santa Cruz Health Services
Goodman Special Care Clinic/LAGLSC
Logan Heights Family Health Center

Mendocino Community Health Clinic
North County Health Project
North East Valley Health Corp.
Russian River Health Center
San Bernardino County
San Francisco Community Clinic
Santa Barbara County Health
Santa Clara Valley Health and Hospital System
St. Mary Medical Center
Tri-City Health Center
University of California San Diego
Watts Health Foundation

Title IV Grantees:

Family Care Network, Children's Hospital, Oakland
Los Angeles Pediatric AIDS Network
Project AHEAD - Health Initiatives for Youth
University of California at San Diego

Title V Grantees:

University of California Los Angeles, School of Dentistry
University of Southern California School of Dentistry

SPNS Grantees:

Bernal Heights Housing Corporation
Harbor-UCLA Research & Education Institute
Lutheran Social Services of Northern California
National Native American AIDS Prevention Center
Bay Area Young Positives, Inc.
Childrens Hospital of Los Angeles
Health Initiatives for Youth
Larkin Street Services
Prototypes
Walden House, Inc.
Northeast Valley Health Corp.

AETC Grantees:

Pacific AIDS Education and Training Center

Subcontractors/Other Interested Agencies

Pittsburg Pre-School Coordinating Council
New Connections

EMA Planning Council, SisterCare
Familias Unidas
EMA Planning Council, WORLD
Catholic Charities
Tranquillium Center/AIDS Community Network
California Conference of Local AIDS Directors
King/Drew Medical Center
UCSD Mother/Child HIV Programs
Mendocino County
CalOptima
UCI Medical Center
UCI College of Medicine
Public Law Center
University of California, Irvine
Hospital Council
AIDS Services Foundation
Laguna Beach Community Clinic
Laguna Shanti
Delhi Center
The Center/AIDS Response Program
Ocean View Internal Medicine
The Living Room
Desert AIDS Project
Office of Maternal and Child Health, Department of Health Services, State of California
Education and Training Unit, Health Care Division, Department of Corrections, State of California
Department of Drug and Alcohol Programs, State of California
Tuberculosis Control Branch, Department of Health Services, State of California
Office of Women's Health, Department of Health Services, State of California
Employment Development Department, State of California
People Living with AIDS Forums hosted by the Office of AIDS, State of California - approx. 44 participants

Appendix 2.

Changes resulting form welfare reform based on federal, state and local legislation, California, January 1998. (Adapted from Riverside/San Bernardino, CA EMA SCSN response)

Before Welfare Reform	After Welfare Reform
Aid to Families with Dependent Children (AFDC)	
How much: $641 per month for a family of four.	Name changes to California Work Opportunities and Responsibility to Kids (CalWORKS) on January 1, 1998. **Adults:** Assistance ends after two years in California for current recipients and 18 months for anyone who begins receiving assistance after January 1, 1998. Adults would be eligible for a total of five years of assistance in a lifetime. **Children:** Time limits do not apply for children.
Supplemental Security Income (SSI)	
What: Assistance for the disabled, and for people 65 and older who have not worked enough to qualify for Social Security. **How much:** Maximum of $640 per month, or $786 per month if recipients live in a board-and-care facility.	**Legal immigrants:** Benefits eliminated for many legal, non-citizen immigrants who were not receiving SSI when President Clinton signed new legislation in August 1996. Some legal residents who are not United States citizens can still receive SSI, including military veterans and those who were living in the country legally prior to August 1996 and later became disabled. (Illegal immigrants have never been eligible.) **Children:** New definitions eliminate some children who previously qualified based on behavioral problems.
Food Stamps	
What: Assistance with groceries for individuals and families. **How much:** Benefits range up to $120 per month for an individual or $400 for a four-person household.	**Program eliminated for:** Legal immigrants between 18 and 64 as of September 1, 1997. (Illegal immigrants have never been eligible.) Able-bodied adults 18 to 50 years of age not participating in work or training program as of December 1, 1997.

Appendix 3

SAMPLE SCSN QUESTIONNAIRE

STATEWIDE COORDINATED STATEMENT OF NEED
(Instructions for response)

The federal guidance for the SCSN does not provide a comprehensive outline for the SCSN but does contain general guidelines. From these guidelines, the Steering Committee has developed the following format for your input.

DISCUSSION OF NEEDS ASSESSMENTS IN CALIFORNIA

- All participants should respond to the following (*we encourage grantees to collaboratively use existing work products that are appropriate for this process; this is not a request or requirement to conduct new needs assessments*):

(1) What formal needs assessments have you conducted?

(2) What tools did you use to conduct your needs assessments?

(3) Identify the barriers you encountered in conducting your needs assessments.

(4) Describe any collaboration among CARE Act grantees in conducting needs assessments.

(5) Describe the needs identified though your needs assessment processes. (Clearly define the need and describe their impact on HIV services and clients.)

(6) Based upon your responses to (1) through (5), identify what you believe should be broad goals for inclusion in the SCSN. State the goal as clearly as possible.

EPIDEMIOLOGIC PROFILE

- The State Office of AIDS will develop a statewide profile
- All participants should respond to the following:

(1) Identify any barriers that you have in accessing epidemiologic data (format, costs, etc.)

(2) How does your service population differ/contract from your county profile?

(3) How is the epidemic changing in your geographic area (i.e., what trends are you seeing over the recent two-year period)?

(4) How do you link epidemiologic data to your needs assessment?

Appendix 3 cont.

CURRENT AND EMERGING ISSUES

Definition of Issue: factors that are happening epidemiologically, socially, medically, economically, or politically that are affecting, or will affect people with HIV or services for people with HIV.

- All participants should respond to the following:

(1) Identify, in rank order, ***current*** issues that affect delivery of HIV services. Respond to (a) and (b) for each issue before proceeding to next.

(a) Clearly define the issue
(b) Describe how and where in your system, the issue is creating critical gaps in services needed by people with HIV.

Note: we will not use your ranking information to prioritize issues in the SCSN; this is for information only.

(2) Identify, in rank order, ***emerging*** issues that will affect delivery of HIV services. Respond to (a) and (b) for each issue before proceeding to next.

(a) Clearly define the issue and describe how it is affecting services and clients.
(b) Describe how and where in your system, the issue is creating critical gaps in services needed by people with HIV.

Note: we will not use your ranking information to prioritize issues in the SCSN; this is for information only.

(3) Based upon your responses to (1) and (2), identify what you believe should be broad goals for inclusion in the SCSN. State the goal as clearly as possible.

PARTICIPATION

(1) Describe how you involved people with HIV in your local process and any creative methods used to encourage participation.

(2) Attach a list of all participants in your local SCSN process. Include each participant's agency affiliation if any; indicate if they are a CARE Act grantee and, if so, identify the Title; and list participants who are willing to be identified as living with HIV.

Data Entry Form

Letter ID	Writer First Name	Writer Last Name	Received Date	Subject
10791	Joe	McCormack	5/6/98	Notification of Appointment

☐ Response Required?

Response Type	Response Date	Responder ID	Responder Name	Action Promised

Action Completed	Action Date	Addressed To

Notes

Sender's Organization	Sender's Street1	Sender's Street2
National Minority AIDS Counci		

Sender's City	Sender's State	Sender's Zip

McCORMACK & ASSOCIATES
• EXECUTIVE SEARCH CONSULTANTS •

April 29, 1998

Ms. Sandy Thurman
Director
Office of National AIDS Policy
750 17th Street, NW, Suite 600
Washington, DC 20503

Dear Sandy:

The National Minority AIDS Council has selected Gwendolyn Mister as its first Deputy Director for Operations. Gwen has been an executive with the American Lung Association since 1987 where she is presently Deputy Director of Field Services. Previous positions have included Director of Accounting at national headquarters and Chief Executive Officer of the Washington, DC chapter.

Gwen has also been active in community affairs, serving as campaign finance advisor and political strategist for Adam Clayton Powell IV for City Council, Kweisi Mfume for Congress, Kurt Schmoke for Mayor and Jesse Jackson for President. Gwen has a degree in economics and accounting from the University of Baltimore.

Our thanks to you and other community members who were of assistance during this long and challenging search. We hope you will join us in wishing Gwen and NMAC Executive Director Paul Kawata every success in managing the growth of the agency.

Sincerely,

Joseph A. McCormack

5042 WILSHIRE BOULEVARD, SUITE 505
LOS ANGELES, CA 90036
(213) 549-9200

April 21, 1998

Ms Sandra Thurman
White House AIDS Policy Director
National AIDS Policy Office
808 17th Street, 8th Floor
Washington, DC 20006

Dear Ms Thurman:

At Home Access Health Corporation, the leader in Telemedicine, we read about your comments at the National AIDS Update Conference with great interest. As the nation's largest provider of anonymous HIV counseling and testing questions with regards to name reporting and partner notification are presented to us on a regular basis.

HOME ACCESS HEALTH
The Leader in Telemedicine

Home Access Health Corporation recognizes the application of named reporting and partner notification for use within the existing public health delivery system. Your image of the camel and the ATM in the desert truly frames the issue. Facts have never more important in understanding HIV than they are now.

The Home Access HIV Counseling and Testing Report which details HIV seroprevalence and demographic data among home test users is one source of those facts. This report is the first published account of national HIV seroprevalence within this population.

The data in the report has been reviewed by the US Centers for Disease Control and Prevention (CDC). The CDC has found the data useful in answering some of the questions raised about the use and potential consequences of at-home HIV testing. The data included in this report consist of all FDA approved at-home HIV tests performed from June 1996 through June 1997 and specific demographic data collected by Home Access Health Corporation from August 1996 through September 1997.

The Home Access® data shows that 57% of people using HIV at-home tests had never been tested before. In addition, greater than 97% of persons using the Home Access® HIV test service, return for their results. Furthermore, 0.9% of those at-home tests were HIV positive. This is a seroprevalence rate three times higher than the estimated 0.3% rate for the population as a whole.

The report underscores that anonymous at-home testing is reaching a population that is not currently being served by other testing alternatives and could prove to be a useful adjunct to existing public health testing initiatives. Unfortunately, there are very few publicly funded programs offering at-home testing at this time. Clearly there is an opportunity to reach economically disadvantaged at risk individuals who would benefit from access to publicly funded at-home testing programs.

For a complimentary copy of *The Home Access HIV Counseling and Testing Report*, please feel free to call at (800) HIV-TEST. Additional information regarding Home Access Health and our products can be found at our website: www.homeaccess.com.

Sincerely,

Joseph T. Smith
Director of Public Health Relations

Home Access Health Corporation / 2401 West Hassell Road, Suite 1510 / Hoffman Estates, IL 60195-5200 / 847 781-2500 / 847 781-2560 Fax

Data Entry Form

Letter ID	Writer First Name	Writer Last Name	Received Date	Subject
10694	Bob	Chase	4/16/98	Thank you

☐ Response Required?

Response Type	Response Date	Responder ID	Responder Name	Action Promised

Action Completed	Action Date	Addressed To

Notes

Sender's Organization	Sender's Street1	Sender's Street2
Nat'l Education Assoc.		

Sender's City	Sender's State	Sender's Zip

nea
NATIONAL EDUCATION ASSOCIATION

Robert F. Chase, President
Reg Weaver, Vice President
Dennis Van Roekel, Secretary-Treasurer

Don Cameron, Executive Director

1201 16th Street, N.W.
Washington, D.C. 20036-3290

April 10, 1998

Ms. Sandra Thurman
Director
Office of National AIDS Policy
750 17th Street NW, Suite 600
Washington, D.C. 20503

Dear Ms. Thurman:

On behalf of the National Education Association, I want to express my appreciation for the leadership of the Clinton Administration in addressing the challenges of the HIV/AIDS epidemic. Specifically, your commitment to ensuring adequate funding and sound policies for HIV prevention has been instrumental in our efforts to combat this disease.

Recently I have learned that the funding for the Centers for Disease Control and Prevention's Business Responds to AIDS/Labor Responds to AIDS Programs is in jeopardy. I urge you to use your leadership to ensure these programs continue to receive the support they need to help labor unions and businesses take action against AIDS.

NEA is the nation's largest professional association, representing 2.3 million members working in public schools. These include classroom teachers, educational support staff, higher education employees, school nurses, and student teachers -- a very diverse workforce united in a common purpose to educate and care for our children.

Even more than protecting workers' health and safety as a labor union, the NEA's efforts to address HIV/AIDS have shown the power of *education* in confronting this disease. The NEA was an early national leader in response to HIV/AIDS and has been instrumental in establishing HIV-related policy guidelines for educational institutions and NEA regional, state and local offices. Thanks to funds received through a cooperative agreement between the NEA Health Information Network and the CDC, we have developed a strong workplace project for our membership and have built partnerships uniting employers, employees, community, parents, and their children in the fight against AIDS.

I hope that we can continue to look to the CDC as a leader in supporting HIV prevention on the frontlines -- and recognizing the workplace as a key opportunity to educate Americans.

Sincerely,

Bob Chase

Bob Chase
President

Data Entry Form

Letter ID	Writer First Name	Writer Last Name	Received Date	Subject
10695	Joseph	McCormack	4/16/98	Request for References

☐ Response Required?

Response Type	Response Date	Responder ID	Responder Name	Action Promised

Action Completed	Action Date	Addressed To

Notes

Sender's Organization	Sender's Street1	Sender's Street2
McCormack & Assoc.		

Sender's City	Sender's State	Sender's Zip

McCORMACK & ASSOCIATES
• EXECUTIVE SEARCH CONSULTANTS •

Ms. Sandy Thurman
Director
Office of National AIDS Policy
750 17th Street, NW, Suite 600
Washington, DC 20503

Dear Sandy:

We have been retained by **Washington State University** (WSU) in Pullman, Washington to recruit a ***Vice President–Business Affairs***, and by **AIDS Healthcare Foundation** (AHF) in Los Angeles to recruit a volunteer ***Treasurer*** for its Board of Trustees.

WSU has an enrollment of over 20,000 with nine colleges, a graduate school and research stations throughout the state. It has an annual operating budget of $550 million with 11,000 people on its payroll. The main campus in Pullman contains over 9.3 million square feet in facilities on 2,000 acres. The Vice President-Business Affairs is one of four direct reports to the President and serves as an integral member of the senior management team for the University. The VP is the Chief Financial Officer of the University and serves as the Treasurer to the Board of Regents. S/he is responsible for a workforce of 2,500, an annual operating budget of $90 million and a biannual capital construction budget in excess of $100 million.

We are seeking a mature professional with significant experience in managing the business, financial and capital management operations of a large university, corporation, municipal entity or government agency. The successful candidate must be familiar with capital construction issues, facilities management, accounting and finance and, ideally, labor relations and human resources. A bachelor's degree is required and a graduate degree in a professionally related field is preferred.

AHF, established in Los Angeles in 1987, is the largest community-based provider of HIV medical care in the U.S. AHF has an annual operating budget of $32 million and a culturally sensitive, ethnically diverse staff of 300 supported by 700 volunteers. The mission of AHF is to provide a full spectrum of quality and affordable health care services to all affected by HIV disease.

We are seeking a senior financial executive with a bank, investment company or public accounting firm. This individual must have 10 years or more of experience with corporate finance, financial planning and reporting. Experience with not-for-profit management and fund accounting is not required, but would be a plus. A graduate degree in business, public administration, accounting, tax or other professionally related field is preferred. A personal interest in the mission of the Foundation is important.

If you can suggest qualified candidates for either position, or if you would like more information, please contact us in confidence at (213) 549-9200. Our resume fax number is (213) 850-1870 and email may be sent to JMSearch@aol.com.

Thank you.

Sincerely,

Joseph A. McCormack

5042 WILSHIRE BOULEVARD, SUITE 505
LOS ANGELES, CA 90036
(213) 549-9200

DAILY NEWS

DEBBIE MEDINA
Director, Ethnic Publications and Sales

March 30, 1998

File
Copy To
Sandy Thurman
Mantaya
Day

FILE
4/9/98

Mr. Tonio Burgos
Tonio Burgos & Associates Inc.
NYPROCOA Inc.
909 Third Avenue
New York, NY 10022

Dear Mr. Burgos:

On behalf of the New York Daily News, I would like to thank you for being part of our AIDS Awareness Magazines Editorial Advisory Board. Your input and assistance in our effort to reach the Latino community with important HIV/AIDS information, is greatly appreciated.

Many of you are already providing resources, information, insight, and guidance, as our editors tackle the development of a bilingual supplement that will cover issues such as; the status of the epidemic in the Latino community, HIV/AIDS prevention, youth and HIV/AIDS, new as well as supplementary treatments for HIV disease, the Air Bridge, and many more. The scope of HIV/AIDS and its impact on and implicatrions for the Latino community, is enormous. This one magazine, could not possibly cover it all. However, the Daily News is committed to responding to community needs and feedback on this initiative to assess future efforts.

Your personal professional commitment to your community, and to the eradication of HIV disease, is both exemplary and inspiring. I am honored to be working with you and other distinguished leaders in the fight against HIV/AIDS.

Sincerely,

Debbie Medina

Data Entry Form

Letter ID	Writer First Name	Writer Last Name	Received Date	Subject
10700	Bruce	Andrews	4/17/98	Meeting decline

☐ Response Required?

Response Type	Response Date	Responder ID	Responder Name	Action Promised

Action Completed	Action Date	Addressed To

Notes

Sender's Organization	Sender's Street1	Sender's Street2
Arnold & Porter		

Sender's City	Sender's State	Sender's Zip

ARNOLD & PORTER
555 TWELFTH STREET, N.W.
WASHINGTON, D.C. 20004-1202
(202) 942-5000
FACSIMILE: (202) 942-5999

NEW YORK
DENVER
LOS ANGELES
LONDON

April 14, 1998

The Honorable Sandra Thurman
National AIDS Policy Director
750 17th Street, NW, Suite 600
Washington, DC 20503

Dear Ms. Thurman:

Recently our mutual friend, Steve Ronnel, mentioned to you our interest in meeting with you to discuss the potential for inconsistent and contradictory regulation of latex by the Occupational Safety and Health Administration ("OSHA") and the Food and Drug Administration ("FDA"). Since that time, it appears that OSHA and FDA are coordinating on new regulations for natural rubber latex. For that reason, we do not want to take up your valuable time at this point, but we appreciate your willingness to meet with us. We thought, however, we should offer some background and perspective on this issue that we hope will be helpful to you in lieu of a meeting.

In response to an increasing number of cases of latex allergy in recent years due to exposure to natural rubber latex, FDA adopted sensible regulations to require labeling of medical products containing natural rubber latex in September 1997. To supplement the labeling requirements, FDA recently drafted new regulations that would establish protein and powder limits for natural rubber latex gloves. The proposed regulations have been forwarded to the Office of Management and Budget, and the new rule should be issued in the next several months.

Because FDA only has jurisdiction over latex in the context of medical devices, OSHA has become involved in order to protect worker health and safety. At the end of 1997, OSHA circulated a draft Hazard Information Bulletin that would have had the effect of strongly discouraging the use of latex and might have created a de facto ban on latex gloves. We were very concerned that this proposed bulletin would cause a "latex scare" and would be detrimental to the public health by discouraging the use of latex products such as gloves and condoms.

On April 6, 1998, we met with Kitty Higgins, the Deputy Secretary of Labor, and Charles Jeffress, the Assistant Secretary of Labor for Occupational Safety and Health, to discuss our concerns. They told us that OSHA has received a significant number of comments on the proposed bulletin and they have decided to substantially modify it to

conform to FDA's approach. We believe that this change is very positive and we are very hopeful that the new bulletin will not have the detrimental effects that the previously proposed bulletin would have caused. OSHA is waiting for the new FDA powder and protein limits, and has agreed to work with interested parties, including the latex glove manufacturing industry, to address their concerns.

In light of the evolution of OSHA's position, a meeting between us at this point would not be an efficient use of your time. We deeply appreciate your interest and will be back in touch with you if the situation changes. Please also do not hesitate to call us if there is anything that we can do to be of assistance or if you have questions about this issue.

Sincerely,

Bruce Andrews

Gordon Li

SITEL®
CORPORATION

April 7, 1998

Ms. Sarah Holewinski
Director, The Office of National AIDS Policy
Special Assistant to the Director
Office of National AIDS Policy
736 Jackson Place, NW
Washington, DC 20503

Dear Ms. Holewinski:

On March 26, Governor Nelson was copied on a letter regarding COBRA coverage for one of our former employees in Atlanta, Georgia, Mr. Jeffery Smith. I want to be sure all of the facts are available to you in this matter.

As an employer of 18,000 people across the globe, SITEL takes its commitment to employees seriously. In fact, one of our core company values stresses the importance of treating fellow employees with honesty and integrity at all times. Put simply, we realize that our employees are our most important asset. Because of this belief, we offer our employees many benefits for their health and well-being, including medical benefits, and short- and long-term disability. In keeping with SITEL's core values, we have provided a full and fair review of Mr. Smith's situation.

The issue raised is in regard to COBRA benefits, which are mandated by federal law. As with all employers who provide COBRA, SITEL is regulated by those federal laws in how we administer the program. The COBRA program has several safeguards in place to protect former employees. COBRA guarantees that participants maintain the same level of benefits as when employed. In addition, notification and payment due dates have long grace periods. Because of this protection and others like it that are provided to COBRA participants, SITEL is comfortable adhering to its deadlines. Following the guidelines consistently for all participants ensures there is no selective applications of these very important benefits.

We recognize that individual circumstances vary. We too struggle with situations which challenge the equitable administration of the program to ensure that every employee is treated fairly and within the plan's guidelines.

7277 World Communications Drive
Omaha, NE 68122
USA
Tel ++1 (402) 963-6810
Wats ++1 (800) 445-6600
Fax ++1 (402) 963-3097
http://www.sitel.com

We also have let Mr. Smith know that if he has any concerns, he may contact the Georgia Department of Insurance. If you have any questions regarding Mr. Smith's COBRA coverage, please feel free to contact me at 402/963-4765.

Sincerely,

Diane Spear
Director, Benefits & Compensation

Enclosure

cc: Michael P. May, Chief Executive Officer, SITEL Corporation
Barry Major, President, SITEL Corporation North America
Jeffery Smith

WHITMAN-WALKER CLINIC INC

MAIN FACILITY
1407 S STREET, NW
WASHINGTON, DC 20009
202-797-3500
TDD 202-797-3547
FAX 202-797-3504

ELIZABETH TAYLOR MEDICAL CENTER
1701 14TH STREET, NW
WASHINGTON, DC 20009
V/TDD 202-745-7000
FAX 202-745-0238

MAX ROBINSON CENTER
2301 M L KING, JR. AVENUE, SE
WASHINGTON, DC 20020
V/TDD 202-678-8877
FAX 202-678-8099

NORTHERN VIRGINIA OFFICE
5232 LEE HIGHWAY
ARLINGTON, VA 22207
703-237-4900
TDD 703-237-3115
FAX 703-237-5757

SUBURBAN MARYLAND OFFICE
7676 NEW HAMPSHIRE AVENUE
SUITE 411
HYATTSVILLE, MD 20783
301-439-0731
TDD 301-439-0733
FAX 301-439-2983

April 9, 1998

Sandra L. Thurman
Director
Office of National AIDS Policy
750 17th Street, N.W.
Washington, DC 20503

Dear Sandy:

I recently became aware of a draft Hazard Information Bulletin (HIB) prepared by the Occupational Safety and Health Administration (OSHA) warning people about the use of natural rubber latex (NRL) gloves and other products. The draft HIB states-

> Use of NRL gloves and other NRL products should be limited as much as possible and other appropriate materials substituted for NRL where employees are at a higher risk of developing NRL sensitivity, such as the health care environment.

As you know, condoms are composed of NRL, and no acceptable alternative non-NRL condom is available. To date, I know of no evidence—anecdotal or otherwise—to suggest that NRL condoms pose a health risk.

I am concerned, however, that release of the draft HIB in final will discourage condom use. If people are being warned that NRL gloves worn on the hands can cause sensitivity and allergic reactions, wearing NRL condoms will seem particularly dangerous.

I believe that any government action, which discourages condom use, could have grave consequences and must be fully justified. It is not clear to me that the draft HIB has received this kind of scrutiny, and I am reasonably certain that little if any thought has been given by OSHA to the impact of the draft HIB on condom use.

I think OSHA should be informed by the Office of National AIDS Policy of the potential harm that could be caused by release of the draft HIB, and urged to how best to deal with these consequences before any HIB is released.

Thank you for your consideration.

Sincerely,

Jim Graham
Executive Director

cc: Charles N. Jeffress, Administrator
Occupational Safety and Health Administration

Michael A. Friedman, Lead Deputy Commissioner
Food and Drug Administration

TKC INTERNATIONAL, INCORPORATED
444 North Capitol Street, N.W. * Suite 841 * Washington, D.C. 20001
Phone: (202) 638-7030 Fax: (202) 638-6784

Washington, May 12, 1998

Ms. Sandy Thurman
Director of Aids
The White House
Washington, D.C. 20500

Dear Ms. Thurman:

Enclosed you will find a letter attached to an article that was sent to Mr. Bob Keefe by Mr. Jorge Noronha, an associate of Mr. Keefe in Rio de Janeiro - Brasil, An article that Mr. Keefe thinks you would be interested in.

Sincerely yours,

Cheryl A. Ali
Assistant

Enc.

JORGE EDUARDO B. DE NORONHA

Rio de Janeiro, April 27, 1998

Mr. Robert J. Keefe
TKC International Inc.
Washington DC - USA

Dear Bob,

As you well know I have been active over the last few years selling products from Cuba's budding biotechnological industry, in Brazil.

I have dealt with recombinant vaccines against Hepatitis B and presently am in the midst of a national sales effort for their recombinant vaccine against cattle tick.

Recently I received the visit of Dr. Manuel Limonta, founder and head of the Centro de Ingenieria Genetica y Biotecnologia - CIGB (Havana). Dr. Limonta told me of recent advances in their project to produce a vaccine against AIDS, which in their case, has already been injected in 25 humans. I felt sure Dr. Limonta would appreciate some awareness and recognition of their efforts from your side. On the occasion he said, quite seriously, although naively, that he would like to invite the First Lady for a visit to the Laboratory and he was sure she would not refuse.

I thought you would like to know of these developments. I also enclose an article featured on Time Magazine on May 13, 1996 (volume 147 - # 20) which gives a fair assessment of Dr.Limonta's Biotec Center.
(http://www.pathfindcr.com/time/magazine/domestic/1996/960513/medicine.html)

Abraços,

Jorge

TIME Magazine

May 13, 1996 Volume 147, No. 20

Return to Contents page

MADE IN CUBA

Fidel Castro's most idiosyncratic venture pays off: Havana is now a leading exporter of biotech products

J. MADELEINE NASH/HAVANA

Gustavo De La Riva's lab boasts an imposing assortment of high-tech gear: automated machines for synthesizing DNA, centrifuges for swirling cell cultures, growth chambers for coddling delicate seedlings. There is even a particle gun that genetically transforms sugarcane embryos by peppering them with DNA-coated BBs. But what really impresses foreign visitors is the folding cot that occupies a corner of De la Riva's office. At the Centro de Ingenieria Genetica y Biotecnologia (CIGB) in Havana, Cuba, De la Riva explains, researchers strive to stay ahead of the competition by sleeping alongside their experiments.

Yes, Cuba--that impoverished island 90 miles and an ideological half-century away from Florida--has begun bootstrapping itself into a biotech minipower. This improbable endeavor ranks as one of the most idiosyncratic of President Fidel Castro's ventures, and despite the anticapitalist rhetoric that resurfaced during last week's May Day celebrations, it may well prove to be the most profitable. The flourishing technological barrio that has sprung up on the outskirts of Havana is not only supplying state-of-the-art health products to local hospitals and clinics but also selling more and more of its goods abroad, bringing in badly needed foreign currency in excess of $100 million a year.

Today Cuba is one of the world's largest producers of a recombinant vaccine against hepatitis B. It is the only producer of a vaccine against the bacterium that causes meningitis B, a particularly nasty form of the disease. It also makes a diverse line of pharmaceuticals: interferon for cancer treatment, epidermal growth factor for wound healing, streptokinase for heart attacks and monoclonal antibodies capable of diagnosing everything from pregnancy to infection with the AIDS virus.

Now Cuba's biotechnicians are expanding into agriculture and industry. Late last year CIGB was host to an international conference at which 250 scientists from the U.S., Europe and South America got a look at some of the products wending their way through the laboratory. Among the most promising: a recombinant vaccine that protects cattle against disease-bearing ticks, crops genetically engineered to repel insects, and industrial enzymes that cut energy consumption.

The Cuban romance with biotechnology began in 1980, when a visiting U.S. physician regaled Castro with tales of the latest wonder drug, interferon. Intrigued, Castro directed Dr. Manuel Limonta, a young Cuban hematologist and immunologist, to set up a facility to manufacture the protein. At first, Limonta and his small staff used human blood cells to produce interferon. But soon the advantages of recombinant DNA technology became apparent, and Limonta started making interferon in giant vats

of genetically engineered yeast.

In 1986 Limonta became director of the brand-new CIGB, which quickly grew into a sprawling research dynamo, one of more than two dozen Cuban institutes dedicated to the biological sciences. The center—along with its marketing arm, a quasi-corporate entity called Heber Biotec—now employs more than 1,200 technicians and scientists. "We don't have an institute of this size devoted to biotechnology in all Australia," marvels Peter Willadsen, a molecular biologist who directs a center on animal diseases in Indooroopilly, Australia.

Cuba's research efforts have been highly pragmatic, aimed at solving real-life problems--of which Cuba has more than its share. Cuban agriculture nearly collapsed following the breakup of the Soviet Union, which for years subsidized Cuba with discount petroleum and petroleum-based fertilizers and pesticides. So scientists at CIGB concentrated on improving the food supply. Among other things, they equipped sugarcane and potatoes with bacterial genes that confer pest resistance and added an extra growth-hormone gene to tilapia, creating a faster-growing variant of that tasty freshwater fish.

CIGB scientists also tried to bolster sagging industrial productivity. Molecular biologist Manuel Raices helped develop a recombinant enzyme that dissolves dextran, a sticky substance that gums up the sugar-refining process. In tests conducted by local sugar mills, the enzyme reduced oil consumption up to 45%. Now Raices is working with Swedish researchers on an enzyme that digests lignin, a gluelike material that bedevils paper manufacturers.

Cuban researchers used to think of themselves as providers of biotechnology to their own country first, then to the Caribbean and finally to large developing nations like Brazil, China and Iran. Thus, Heber provides all Cuban newborns with the hepatitis-B vaccine for free and charges countries like India as little as $2 a shot. But the "special period"--as Cubans euphemistically refer to the economic crisis that followed the Soviet withdrawal—has redrawn these priorities, and Cuba's biotechnicians are entertaining larger ambitions. "We have the technology," declares Julio Delgado, who heads CIGB's industrial-enzyme program. "Now we're looking for partners with money."

Joint ventures with foreign firms could bolster Cuba's credibility in the global biotech marketplace. While Cuban institutions conduct clinical trials of vaccines and drugs and informally follow U.S. guidelines for field-testing recombinant organisms, the perception persists that Cuba sometimes releases its products prematurely. Recently, for example, scientists at the Citrus Institute developed a monoclonal antibody to detect tristeza, a lethal virus that threatens to devastate the Caribbean citrus industry. However, although the antibody works well in Cuba, it is being offered to countries whose crops may be infected with different strains.

Cuba clearly appeals to foreign pharmaceutical firms. It occupies a strategic location on the edge of major markets in North and South America and boasts more than 5,000 scientists and technicians—a skilled work force that is, by Western standards, grossly underpaid (average monthly salary: 400 pesos, or about $10). Peter Scott, chief executive of London-based Feta Funds Ltd., estimates that a European drugmaker could produce its drugs in Cuba for one-tenth the cost of local production.

Right now, however, the U.S. trade embargo prohibits American drug and chemical companies, Cuba's natural partners, from establishing joint ventures. The embargo likewise dissuades big European companies from striking deals with Cuba because products made in Havana cannot be sold in the U.S., which represents 50% of the global market for pharmaceuticals.

No one awaits the lifting of the U.S. embargo more eagerly than Cuban scientists, who struggle to obtain basic supplies--chemical reagents, for instance--that in the U.S. are but a phone call away, and whose incomes are starting to trail behind those of service workers buoyed by Cuba's rising tourist trade. CIGB has reportedly started paying its scientists partly in dollars to keep them from leaving the field. "I love my research," confides a hardworking scientist. "But if I have to drive a taxi to support my family, I will."

For scientists who are solving nature's intricate puzzles, the political obstacles that prevent them from working with U.S. colleagues seem relatively easy to solve. "All we require," says De la Riva, "is relaxation by the politicians, and then we can do great work together." Alas, for him and his friends, the crisis triggered by the downing of two U.S. planes in February has made that possibility seem more distant than ever.

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From Bruce Reed (?)

CHIEF OF STAFF TO THE PRESIDENT

(1) Send copy to Bruce Reed to prepare a response.

(2) Make copy for POTUS

SARAH/SANDY -

We need a standard response.

-BR

NANCY PELOSI
8TH DISTRICT, CALIFORNIA

2457 RAYBURN BUILDING
WASHINGTON, DC 20515-0508
(202) 225-4965

DISTRICT OFFICE:
FEDERAL BUILDING
450 GOLDEN GATE AVENUE
SAN FRANCISCO, CA 94102-3460
(415) 556-4862
sf.nancy@mail.house.gov
http://www.house.gov/pelosi

Congress of the United States
House of Representatives
Washington, DC 20515-0508

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CONGRESSIONAL WORKING GROUP ON CHINA, CHAIR

AT-LARGE WHIP

April 10, 1998

Cop
Pozner
Prepare response

Erskine Bowles
Chief of Staff
The White House
Washington, D.C. 20500

Dear Erskine:

It is my understanding that the Administration is nearing a decision on lifting the ban on federal funding for needle exchange programs.

As a member of the Appropriations Subcommittee on Labor-Health and Human Services-Education, I helped craft the compromise that established a moratorium on funding for needle exchange until March 31 of this year. The purpose of the moratorium was to give Congress enough time to act on prohibiting the lifting of the ban. While hearings were held in Congress by both the appropriating and authorizing committees during the moratorium, no action to prohibit the funding has occurred.

Those of us advocating lifting the ban on federal funding know that the decision must be based on the science. The science is in, and the facts are clear. Needle exchange programs reduce HIV transmission and do not increase drug use.

I have a thorough knowledge of needle exchange programs in San Francisco, Washington, D.C., and Baltimore and believe they demonstrate very clearly the efficacy of needle exchange programs.

Needle exchange saves lives. I encourage the Administration to lift the ban.

Sincerely,

Nancy

NANCY PELOSI

Dear Erskine;
I hope you have a Happy Easter!
N.