

# Expanding Access to HIV Care in California

STEPHEN MORIN, MYRNA COZEN, AUDREY KETTANEH, FRED BENTLEY - AIDS Policy Research Center (APRC), AIDS Research Institute, University of California, San Francisco  
 KAARINA ORNELAS, DANA VAN GORDER, FRED DILLON - San Francisco AIDS Foundation (SFAF)

Contact information:  
 Myrna Cozen  
 AIDS Research Institute  
 Univ. of California, San Francisco  
 mcozen@psg.ucsf.edu

## Abstract

**Objective:** A group of related policy options are being debated at both the federal and state levels that could extend health care coverage to people in early stages of HIV disease who do not have coverage or are in danger of losing their coverage. The purpose of this project is to develop uniform measures to assess the relative merit of these policy options for expanding access to HIV care in California. Six specific policy options have been identified through analysis of introduced legislation and through discussions with state AIDS office staff, legislative staff and representatives of consumer organizations. The overall goal of the project is to improve the uniformity and quality of the data used by advocates and policy-makers for policy development and for evaluating legislative options.

### Specific Aims:

- To systematically characterize each of the proposed options in terms of target population, eligibility criteria, benefits, cost per unit of service, and legislative or regulatory changes required for implementation.
- To develop cost estimates, using spreadsheet models, for each of the options, including their impact on California's state budget.
- To conduct key informant interviews with state legislative staff, public health officials, HIV medical care providers, treatment advocates, and people living with HIV to assess the acceptability and feasibility of these policy options.

## Background

- Advances in medical treatment have resulted in a steady increase in the number of people living with HIV infection and AIDS in the United States, presenting a challenge for the provision of appropriately timed medical care, including pharmaceutical treatment.
- Federal treatment guidelines, currently being updated, recommend that regular laboratory monitoring—including plasma HIV RNA, CD4+ T cell counts and HIV drug resistance testing—and Highly Active Antiretroviral Treatment should be offered to individuals before they show signs of immune system deterioration.
- The guidelines create a context for federal and state policy makers to consider important questions regarding access to care and treatment for individuals in earlier stages of HIV disease.
- Results from the HIV Costs, Services and Utilization Project (HCSUS) suggest that nearly 70% of patients with HIV disease depend on public programs or personal assets to finance their medical care. Medi-Cal and Medicare, the two major entitlement programs offering health care coverage to low income individuals in California, require that people with HIV disease be fully disabled by an AIDS diagnosis before qualifying for coverage. Income eligibility criteria for Medi-Cal (recently raised from 75% of the federal poverty level (FPL) to 100 % FPL) is very restrictive.
- This set of circumstances has informed our decision to focus on developing policy options for expanding health care coverage for low to moderate income people with HIV disease in California, who are not yet disabled by an AIDS diagnosis, and to do so in such a way as to maximize use of the health care infrastructure that already is in place.

	OPTION 1: EXPAND MEDICAL ELIGIBILITY FOR INDIVIDUALS IN THE EARLY STAGES OF HIV DISEASE THROUGH A MEDICAL WAIVER	OPTION 2: EXPAND MEDICAL ELIGIBILITY FOR INDIVIDUALS IN THE EARLY STAGES OF HIV DISEASE THROUGH THE USE OF CALIFORNIA ONLY FUNDS	OPTION 3: DEVELOP A RETURN-TO-WORK MEDICAL PROGRAM FOR INDIVIDUALS WITH HIV WHO RETURN TO WORK FROM DISABILITY	OPTION 4: OBTAIN FEDERAL DEMONSTRATION PROJECT FUNDS FOR MEDICAL COVERAGE TO INDIVIDUALS WITH POTENTIALLY DISABLING MEDICAL CONDITIONS PRIOR TO THE ONSET OF DISABILITY	OPTION 5: EXPAND THE PURCHASE OF PRIVATE HEALTH INSURANCE THROUGH THE ANNUAL WHITE FUNDED HEALTH INSURANCE PREMIUM PROGRAM (CAREHIP)	OPTION 6: CREATE AN ADAP PLUS PROGRAM TO PROVIDE LABORATORY CARE FOR UNINSURED AND UNDERINSURED INDIVIDUALS WITH HIV DISEASE
<b>BENEFITS</b>	<ul style="list-style-type: none"> <li>Federally financed coverage for individuals with early HIV disease</li> <li>Option covers both drugs and other healthcare services</li> <li>Follow-up care, including laboratory monitoring, and drug treatment, for individuals in early stages of HIV has been shown to slow progression to AIDS substantially</li> </ul>	<ul style="list-style-type: none"> <li>State-financed coverage for individuals with early HIV disease</li> <li>Option covers both drugs and other healthcare services</li> <li>Follow-up care, including laboratory monitoring and drug treatment, for individuals in early stages of HIV has been shown to slow progression to AIDS substantially</li> <li>Not likely to be pursued unless it results in the net cost savings to state</li> </ul>	<ul style="list-style-type: none"> <li>Allow disabled individuals to re-enter workforce without losing health care benefits</li> <li>Approximation of \$20-250 per month will be charged for Medi-Cal coverage</li> <li>To benefit, an individual must have a "disabled" determination from the Social Security Administration, but does not need to receive SSI or SSDI in order to become eligible</li> <li>The state is free to set the income cap, even to eliminate it, that determines eligibility for the Medicaid buy-in program</li> </ul>	<ul style="list-style-type: none"> <li>Enables state to extend Medicaid to individuals with conditions that, without ongoing healthcare, would eventually qualify them for Social Security disability benefits</li> <li>Beneficiaries receive the same benefits and pay the same premiums as workers with disabilities</li> <li>Follow-up care, including laboratory monitoring and drug treatment, for individuals in early stages of HIV has been shown to slow the onset of debilitating HIV-associated conditions</li> <li>Demonstration Project will provide new information on the cost-effectiveness of early health care intervention for people with potentially disabling conditions</li> </ul>	<ul style="list-style-type: none"> <li>Modeled on Florida's successful AIDS Insurance Continuation Program, the state assumes payment of private insurance premiums for HIV-infected individuals who can no longer afford them</li> <li>The state would use Ryan White (and possibly general revenue) funds to pay all or part of the insurance premiums for HIV-infected individuals in danger of losing their coverage</li> <li>Provides continuity of care and reduces the need to access public assistance programs</li> <li>Depending on income level, beneficiaries would pay share of cost of monthly insurance premium</li> <li>New services could include state payment of insurance co-payment and deductibles</li> </ul>	<ul style="list-style-type: none"> <li>Modeled on New York State's successful ADAP Plus Program, this program would include comprehensive medical, social, dental, HIV disease monitoring, and HIV-related drug treatment</li> <li>Eligibility would be extended to all those who meet ADAP income eligibility criteria and lack other options for essential primary care coverage</li> <li>California state funds and Ryan White Title III and Title II funds would be used to cover the costs of this program</li> </ul>
<b>ELIGIBILITY MODEL</b>	<ul style="list-style-type: none"> <li># of HIV-infected people who know their status</li> <li># of people with AIDS diagnosis</li> <li>maximum # of HIV-infected people who could be made categorically eligible</li> <li># of potentially categorically eligible individuals who don't have insurance</li> <li># of potentially categorically eligible individuals who are at or below 100% FPL (or 133% FPL for potentially medicaid needy)</li> <li># of potentially eligible beneficiaries who would take advantage of the benefit</li> <li>connected for 1% who would progress to AIDS</li> </ul>	<ul style="list-style-type: none"> <li># of HIV-infected people who know their status</li> <li># of people with AIDS diagnosis</li> <li>maximum # of HIV-infected people who could be made categorically eligible</li> <li># of potentially categorically eligible individuals who don't have insurance</li> <li># of potentially categorically eligible individuals who are at or below 100% FPL (or 133% FPL for potentially medicaid needy)</li> <li># of potentially eligible beneficiaries who would take advantage of the benefit</li> <li>connected for 1% who would progress to AIDS</li> </ul>	<ul style="list-style-type: none"> <li># of disabled HIV-infected individuals in CA</li> <li># of disabled HIV-infected individuals in CA on Medi-Cal</li> <li># of HIV-infected Medi-Cal beneficiaries who would enter the workforce</li> <li># of workforce entrants who earn less than 250% FPL and would lose Medi-Cal benefits</li> <li># of potential eligibles who would participate in the buy-in program</li> </ul>	<ul style="list-style-type: none"> <li># of individuals with HIV aged 16-64 in CA who know their status</li> <li># of people with HIV 16-64 who are employed</li> <li># of employed HIV-infected adults who lack health insurance</li> <li># of employed HIV-infected adults whose income does not exceed 450% FPL</li> <li># of individuals who would participate in the "Buy-in" program</li> </ul>	<ul style="list-style-type: none"> <li># of HIV-infected individuals who know their status</li> <li># of HIV-infected people with private health insurance</li> <li># of privately-insured individuals who earn less than 300% FPL</li> <li># of privately-insured individuals with HIV who earn less than 300% FPL and are likely to lose private coverage</li> <li># of individuals who are likely to lose coverage and are not already covered by CAREHIP</li> <li># of potential beneficiaries who would participate in expanded CAREHIP program</li> </ul>	<ul style="list-style-type: none"> <li># of people who are HIV-infected and know their status</li> <li># of HIV-infected people who do not have drug coverage</li> <li># of HIV-infected people without drug coverage who earn up to 500% FPL</li> <li># of potential ADAP beneficiaries who actually enroll in ADAP</li> <li># of ADAP enrollees without any other form of insurance</li> <li># of potential beneficiaries of expanded ADAP who would enroll</li> <li>connected # of potential enrollees who progress to AIDS</li> </ul>
<b>COST MODEL</b>	<ul style="list-style-type: none"> <li>a) for individuals currently infected with HIV <ul style="list-style-type: none"> <li>estimated cost of recommended combination therapy</li> <li>estimated cost of monitoring 4 times a yr.</li> <li>individuals who would only be monitored</li> <li>costs for monitoring</li> <li>individuals who would require monitoring and comb. therapy</li> <li>costs for drugs and monitoring</li> <li>Total for drugs and monitoring</li> </ul> </li> <li>b) for individuals who become infected in years 2-5 <ul style="list-style-type: none"> <li># of newly-infected individuals each year</li> <li># of newly-infected individuals who know their status</li> <li># of individuals who meet income and asset requirements</li> <li># of individuals who would participate in program</li> <li># of individuals who would only be monitored</li> <li>costs for monitoring</li> <li># of individuals who would require monitoring and comb. therapy</li> <li>costs for drugs and monitoring</li> <li>total for drugs and monitoring for individuals who became infected in years 2-5</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>a) for individuals currently infected with HIV <ul style="list-style-type: none"> <li>estimated cost of recommended combination therapy</li> <li>estimated cost of monitoring 4 times a yr.</li> <li>individuals who would only be monitored</li> <li>costs for monitoring</li> <li># of individuals who would require monitoring and comb. therapy</li> <li>costs for drugs and monitoring</li> <li>Total for drugs and monitoring</li> </ul> </li> <li>b) for individuals who become infected in years 2-5 <ul style="list-style-type: none"> <li># of newly-infected individuals each year</li> <li># of newly-infected individuals who know their status</li> <li># of individuals who meet income and asset requirements</li> <li># of individuals who would participate in program</li> <li># of individuals who would only be monitored</li> <li>costs for monitoring</li> <li># of individuals who would require monitoring and comb. therapy</li> <li>costs for drugs and monitoring</li> <li>total for drugs and monitoring for individuals who became infected in years 2-5</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>a) for individuals currently infected with HIV <ul style="list-style-type: none"> <li>estimated total cost of Medi-Cal benefits for individuals with AIDS</li> <li># of potential enrollees in the buy-in program</li> <li>estimated total cost for all potential enrollees</li> </ul> </li> <li>b) for HIV-infected individuals who become disabled in years 2-5 <ul style="list-style-type: none"> <li># of HIV-infected individuals who would lose AIDS and enroll in Medi-Cal</li> <li># of new Medi-Cal beneficiaries who enter the workforce</li> <li># of workforce entrants who earn less than 250% FPL and would lose Medi-Cal benefits</li> <li># of potential eligibles who would participate in the buy-in program</li> <li>estimated total cost of Medi-Cal benefits for an individual with AIDS</li> <li># of potential enrollees in the buy-in program</li> <li>estimated total cost for all potential enrollees who become disabled in years 2-5</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>a) for individuals currently infected with HIV <ul style="list-style-type: none"> <li>average premium paid out for individuals currently infected with HIV</li> <li># of potential enrollees in the buy-in program</li> <li>estimated total cost for currently-infected potential enrollees</li> </ul> </li> <li>b) for HIV-infected individuals who become disabled in years 2-5 <ul style="list-style-type: none"> <li># of newly-infected individuals with HIV aged 16-64 who know their status</li> <li># of newly-infected individuals with private health insurance</li> <li># of newly-infected, privately-insured individuals with HIV who earn less than 300% FPL</li> <li># of newly-infected, privately-insured individuals with HIV who earn less than 300% FPL and are likely to lose private coverage</li> <li># of newly-infected individuals who would participate in the "buy-in" program</li> <li>estimated total costs of all newly-infected enrollees</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>a) for individuals currently infected with HIV <ul style="list-style-type: none"> <li>Average premium paid out for individuals currently enrolled in CAREHIP</li> <li># of potential beneficiaries who would participate in expanded CAREHIP program</li> <li>total cost for currently-infected</li> </ul> </li> <li>b) for individuals who become infected in years 2-5 <ul style="list-style-type: none"> <li># of individuals who became infected and know their status</li> <li># of newly-infected individuals with private health insurance</li> <li># of newly-infected, privately-insured individuals with HIV who earn less than 300% FPL</li> <li># of newly-infected, privately-insured individuals with HIV who earn less than 300% FPL and are likely to lose private coverage</li> <li># of individuals who are likely to lose coverage and are not already covered by CAREHIP</li> <li># of potential beneficiaries who would participate in expanded CAREHIP program</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>a) for individuals currently infected with HIV <ul style="list-style-type: none"> <li>estimated cost of 5 outpatient visits and 4 viral load tests, per beneficiary</li> <li># of potential beneficiaries in ADAP expansion program</li> <li>total cost of expanded ADAP for individuals currently infected with HIV</li> </ul> </li> <li>b) for individuals who become infected in years 2-5 <ul style="list-style-type: none"> <li># of newly-infected individuals each year</li> <li># of newly-infected individuals who know their status</li> <li># of individuals who meet requirements for expanded ADAP</li> <li># of potential beneficiaries who would participate in program</li> <li>estimated cost of 5 outpatient visits and 4 viral load tests, per beneficiary</li> <li># of potential beneficiaries in ADAP expansion program</li> <li>total cost of expanded ADAP for individuals who become infected in years 2-5</li> </ul> </li> </ul>
<b>COST SAVINGS</b>						
<b>PREMIUM REVENUES</b>			<ul style="list-style-type: none"> <li>weighted average of premium charged to enrollees</li> <li>average share of cost or co-payment amount</li> <li>estimated total cost for all potential enrollees</li> </ul>	<ul style="list-style-type: none"> <li>average premium amount</li> <li>average share of cost or co-payment amount</li> <li>estimated number of enrollees who would contribute a share of cost</li> </ul>		
<b>MEDI-CAL</b>	<ul style="list-style-type: none"> <li># of program participants prevented from progressing to AIDS</li> <li>estimated annual cost of treating individual with AIDS who are on Medi-Cal</li> <li>total cost of drugs and monitoring under the expanded ADAP</li> <li>estimated Medi-Cal savings</li> </ul>	<ul style="list-style-type: none"> <li># of program participants prevented from progressing to AIDS</li> <li>estimated annual cost of treating individual with AIDS who are on Medi-Cal</li> <li>total cost of drugs and monitoring under the expanded ADAP</li> <li>estimated Medi-Cal savings</li> </ul>			<ul style="list-style-type: none"> <li># of program participants prevented from progressing to AIDS</li> <li>estimated annual cost of treating an individual with AIDS who are on Medi-Cal</li> <li>total cost of drugs and monitoring under the expanded ADAP</li> <li>estimated Medi-Cal savings</li> </ul>	<ul style="list-style-type: none"> <li># of program participants prevented from progressing to AIDS</li> <li>estimated annual cost of treating an individual with AIDS who are on Medi-Cal</li> <li>total cost of drugs and monitoring under the expanded ADAP</li> <li>estimated Medi-Cal savings</li> </ul>
<b>SSI</b>	<ul style="list-style-type: none"> <li># of program participants prevented from progressing to AIDS</li> <li>estimated cost of federal SSI benefit</li> <li>estimated SSI savings</li> </ul>	<ul style="list-style-type: none"> <li># of program participants prevented from progressing to AIDS</li> <li>estimated cost of federal SSI benefit</li> <li>estimated SSI savings</li> </ul>	<ul style="list-style-type: none"> <li>average amount of reduction in SSI benefits</li> <li># of potential enrollees in the buy-in program who would experience a reduction in SSI benefits</li> <li>estimated SSI savings</li> </ul>	<ul style="list-style-type: none"> <li>average amount of SSI benefits</li> <li>total SSI savings</li> </ul>	<ul style="list-style-type: none"> <li># of program participants prevented from progressing to AIDS</li> <li>estimated cost of federal SSI benefit</li> <li>estimated SSI savings</li> </ul>	<ul style="list-style-type: none"> <li># of program participants prevented from progressing to AIDS</li> <li>estimated cost of federal SSI benefit</li> <li>estimated SSI savings</li> </ul>
<b>ADAP</b>				<ul style="list-style-type: none"> <li>average drug cost for ADAP beneficiaries</li> <li># of individuals who would lose private coverage</li> <li># of individuals who would lose private coverage and enroll in ADAP</li> <li>estimated ADAP savings</li> </ul>	<ul style="list-style-type: none"> <li>average drug cost for ADAP beneficiaries</li> <li># of individuals who would lose private coverage</li> <li># of individuals who would lose private coverage and enroll in ADAP</li> <li>estimated ADAP savings</li> </ul>	<ul style="list-style-type: none"> <li># of program participants prevented from progressing to AIDS</li> <li>estimated cost of outpatient and monitoring services for current and newly-infected individuals</li> <li>Medi-Cal savings + SSI savings</li> </ul>
<b>TOTAL ESTIMATED COST</b>	<ul style="list-style-type: none"> <li>unadjusted program cost (total cost of monitoring and drugs for current and newly-infected individuals)</li> <li>Medi-Cal savings + SSI savings</li> </ul>	<ul style="list-style-type: none"> <li>unadjusted program cost (total cost of monitoring and drugs for current and newly-infected individuals)</li> <li>Medi-Cal savings + SSI savings</li> </ul>	<ul style="list-style-type: none"> <li>unadjusted program cost (total cost of Medi-Cal benefits for current and newly-infected individuals)</li> <li>Premium revenues + SSI savings</li> </ul>	<ul style="list-style-type: none"> <li>unadjusted program cost (total cost of Medi-Cal benefits for current and newly-infected individuals)</li> <li>ADAP savings + Medi-Cal savings + SSI savings</li> </ul>	<ul style="list-style-type: none"> <li>unadjusted program cost (total cost of monitoring and drugs for current and newly-infected individuals)</li> <li>ADAP savings + Medi-Cal savings + SSI savings</li> </ul>	<ul style="list-style-type: none"> <li>unadjusted program cost (total cost of outpatient and monitoring services for current and newly-infected individuals)</li> <li>Medi-Cal savings + SSI savings</li> </ul>
<b>KEY INFORMANT ASSESSMENT</b>	<ul style="list-style-type: none"> <li>Strong support</li> <li>Concern that without raising income eligibility levels, the majority of individuals in need of coverage could not benefit from this option</li> <li>Concern that implementation of a waiver might jeopardize other sources of funding or replace other health care programs for people with HIV disease</li> </ul>	<ul style="list-style-type: none"> <li>Moderate support</li> <li>Concerns about the political feasibility of the option</li> <li>Concerns that implementation of a waiver might jeopardize other sources of funding or replace other health care programs, especially any that heavily rely on CA funds, for HIV-infected people</li> </ul>	<ul style="list-style-type: none"> <li>Currently available in California as a result of AB 155 passed in 1999, but minimally utilized</li> <li>Concern that option provides support only for individuals who choose to work, part-time or otherwise, to jobs where health care is not a benefit</li> <li>Concerns that people who are on disability may not choose to return to work, and that people who do return to work will often return to jobs that provide health care coverage</li> </ul>	<ul style="list-style-type: none"> <li>Moderate support</li> <li>Concern that few people would take advantage of this option, potential eligibles likely to continue working until they could qualify for disability</li> </ul>	<ul style="list-style-type: none"> <li>Moderate to minimal support</li> <li>Concern that this option might be useful to ensure continuing coverage for those who are already insured, but would do nothing to help people who have already lost private coverage</li> <li>Prefer to redirect effort on reforming insurance industry so that insurers not continue to charge high premiums for people with HIV</li> </ul>	<ul style="list-style-type: none"> <li>Moderate support</li> <li>Concern that this option would not work in CA, because it would require a significant alteration of Title II spending</li> </ul>

## Development of Cost Estimates

- Cost estimates are being developed for each of the policy options using adaptations of the model developed by Morin and Charlebois.
- These estimates focus on the impact each options would have on the California state budget.
- Medi-Cal and ADAP data on the cost of HIV-related care and on the patterns of utilization of such care are being analyzed for incorporation into the models.
- Assumptions and inputs will be justified by empirical evidence whenever possible.
- The final models must be both technically accurate and presented in a format that is easily understood by policymakers and consumer advocates.

## Analysis of Cost Data

- Medi-Cal cost data for HIV/AIDS related care and services were reviewed and analyzed. Preliminary results indicate that
  - Medi-Cal costs for HIV/AIDS related services have increased consistently since 1996
  - HIV/AIDS related drug costs to the Medi-Cal program increased nearly 2 1/2 times from 1996 through 1999.
  - HIV/AIDS related inpatient costs declined 31% during this same period
  - The number of individuals receiving HIV/AIDS related services through Medi-Cal increased 23% during this period.

## Key Informant Interviews

- We are conducting key informant interviews with state legislative staff, public health officials, HIV medical care providers, treatment advocates and people living with HIV disease. The purpose of the interviews is to assess the acceptability and feasibility of each of the policy options for expanding health care coverage to people in earlier stages of HIV disease. Although the interviews are ongoing, preliminary results suggest:
  - There is substantial support for efforts to expand eligibility criteria for Medi-Cal;
  - The capacity of people with HIV disease to purchase private health insurance should be expanded;
  - Rural specialty care needs to be improved or made more accessible;
  - The issue of HIV care for undocumented people with HIV needs to be examined;
  - Outreach and treatment education need to be a priority in expanding access to HIV care.



University of California  
 San Francisco

**UCSF**  
 AIDS Research Institute

**UARP Award # PC99-SFAF-2025**