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Senate Bill 1251 Home Health Attendant or Hospice Care Pilot Study

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CALIFORNIA LEGISLATURE
SENATOR DAVID ROBERTI
PRESIDENT PRO TEMPORE

SENATE BILL 1251
HOME HEALTH ATTENDANT OR HOSPICE CARE PILOT STUDY
April 1, 1986 to May 31, 1987

Jack Little, Ph.D
Steve Daley, M.A.
Howard Fortson

AIDS Project Los Angeles
Los Angeles, California
September 1987

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Introduction

Senate Bill 1251 (Chapter 767, Statutes of 1985) authorized the Department of Health Services to award contracts within the counties of Los Angeles, San Francisco, San Diego, Alameda, and Santa Barbara to conduct pilot care projects and analyze the costs of Home Health Attendant or Hospice Care (HHAHC) for persons with AIDS or ARC. The AIDS Project Los Angeles received the contract for Los Angeles County. The original award was in the amount of $440,000, with $40,000 to be passed on to Orange County through a subcontract. The award was effective as of April 1, 1986 to continue through March 31, 1987. Subsequent augmentation increased the total funding and extended the project to June 30, 1987.

The HHAHC Pilot Project was designed to provide home health attendant or hospice care for not less than 125 persons with AIDS or ARC. This care was to be provided through an intensive program of case management drawing upon all available community resources. All available sources of funding were to be used to provide services and generate data prior to the expenditure of project funds. Subcontracts were let to home nursing agencies and registries, hospice, and emotional support groups to provide services not available within AIDS Project Los Angeles. "Buddies", food, transportation, emergency housing, and other volunteer services were provided by AIDS Project Los Angeles.

Staff, consisting of the Project Director (Principal Investigator), Project Administrator, Case Managers, Administrative Assistant, and other clerical and data processing support were provided through the project.

The death of the original Project Director (Dr. Carol Quinn) required a total restructuring of the project staff. Jack Little, Ph.D. assumed responsibility as Principal Investigator two months into the project. He was subsequently named as Project Director and assumed responsibility for the total project. Changes in personnel at the Department of Health Services, Office of AIDS occurred at approximately the same time.

A review of the goals and objectives of the project required that major modifications of design and program be initiated. The focus of the project was shifted from provision of direct services to persons with AIDS or ARC to the generation and collection of specific data through the provision of services. This was accomplished through the development of a systematic approach to the capture and reporting of all data related to the provision and purchase of services. The development of the data catchment system, and computer software for recording and analyzing the data, provided the structure necessary for the accomplishment of the project goals and objectives.

Additional modifications were required as the Visiting Nurses Association of Los Angeles, which had a sole source subcontract for provision of attendant and intermittent skilled nursing services for subjects on the study, found that they could not continue to provide such services after August 31, 1986. The cost of the provision of services and low reimbursement through Medi-Cal made it fiscally impossible for them to continue. Subcontracts were initiated with six (6) other home health care organizations or nursing registries. Also, the AIDS Service Foundation of Orange County withdrew from the project.

Resources which were assumed to be available in the community were not. The most notably lacking was professional mental health services. It has been impossible to access the State hospital system for persons experiencing severe psychiatric problems related to AIDS. In one documented case, a subject, who was blind and experiencing various psychiatric symptoms, struck an attendant, threatened an attendant with a chair, and talked of suicide. When a Psychiatric Evaluation Team was called, they refused to respond, indicating that there was insufficient evidence that he was a danger to himself or others. He died in an acute care hospital where he was placed by his physician. The community mental health services appear to be highly overtaxed and without adequate funding to provide services for the majority of persons with AIDS.

There are no skilled nursing facilities in Southern California which will accept a person with AIDS. This lack of service results from several factors:

1. Demand for beds for care for the elderly.
2. Low level of Medi-Cal reimbursement
3. Lack of understanding of the disease by service providers.
4. Additional staff training required to provide proper care.
5. Fear and lack of information on the part of the public.

It must also be noted, however, that while it was assumed that there is a high need for skilled nursing beds, such an assumption may not be valid. The majority of the care which was assumed to require skilled nursing, on this study, has been accomplished in the home using a combination of attendants and intermittent skilled nursing.Residential care facilities for persons with AIDS are not available in the Los Angeles area. There are five (5) homes in the Long Beach area and AIDS Project Los Angeles has one home in Los Angeles which are used to provide shelter for persons with AIDS. These homes are not licensed as Residential Care Facilities. They are shared dwellings where four or five individuals live and receive what care they can secure through the various AIDS organizations and other community efforts. Individuals with AIDS have been known to sleep in parks or on the streets. Such individuals are frequently not acceptable to shelters or hotels. They frequently exhibit irrational behavior or demonstrate characteristics of mental illness. It appears that many of these individuals could be accommodated in a Residential Care Facility.

At the beginning of the pilot study, it was assumed that there would be a need for extensive hospice services. There is no provision for licensing Hospice facilities in California. Hospice is an interdisciplinary program which provides for the physical, emotional, social and spiritual needs of the patient and his family or significant others, during the terminal phase of illness. This includes symptom management and pain control, as well as bereavement counseling. If defined as above, virtually all the subjects of this study have been in a home hospice program. If hospice is defined in terms of meeting the criteria for reimbursement for services, the need for hospice services has not been demonstrated. Only three subjects elected such hospice programs. The majority are not willing to forsake aggressive treatments or to accept a prognosis of six months or less. In many cases, physicians are as reluctant as are patients to accept hospice care. Those who have elected hospice care, have elected home hospice rather than a residential hospice program. Originally, it was assumed that there would be a need for a large residential hospice program. However, until, or unless, the Medicare requirements for hospice care for persons with AIDS are modified, it appears that there is limited need for residential hospice programs for persons with AIDS.

The Home Health Attendant or Hospice Care Pilot Project conducted by AIDS Project Los Angeles provided a total of 71,390.67 hours of services to persons with AIDS or ARC from April 1, 1986 through May 31, 1987. These services were provided to 137 individuals, each receiving an average of 521.10 hours of service at an average cost of $6,569.93 per client. The majority of the units of service (437.42 hours; $4,536.86 per person) were for attendant care. It is interesting to note that individuals with AIDS who received services through Medi-Cal required more services than did those who had private insurance or no insurance.

Another aspect of the project was the evaluation of both client and physician satisfaction. As of May 31, 1987, both clients and physicians indicated a high level of satisfaction. Clients indicated a 3.77 level of satisfaction, on a five point scale, while physicians reported a 2.68 level of satisfaction on a three point scale.

This study is one of five which has been conducted throughout the State. At a meeting of the Pilot Project Directors in December 1986, it was decided that all of the pilot projects would use the same data format and data collection procedures. It was further agreed that all data would be provided to the AIDS Project Los Angeles Pilot Project for analysis and the development of the final report. The report which follows is limited to the data collected through the AIDS Project Los Angeles Pilot Care Project.

Scope of the Study

The mandate for this study is specified in SB 1251 (Chapter 767 Statutes of 1985). The cost effectiveness of home health attendant or hospice care was to be demonstrated as an alternative to long term acute care hospitalization of individuals with AIDS or ARC. This presented many research problems. The national mean daily hospital charge for a patient with AIDS was reported by Dr. Ann Hardy of the Centers for Disease Control as $878, while the Hospital Council of Southern California reported the mean daily charge in Southern California at $963. A 1985 survey by the Hospital Council of Southern California found that the average length of each hospitalization for a person with AIDS was 17.3 days. L.A. County-U.S.C. Medical Center reported a reduction in the number of days of each hospitalization from 21 days to 17.3 days by May of 1986. Each patient averaged three hospitalizations during the course of his illness. The reduction of the number of days of hospitalization for persons with AIDS was attributed primarily to alternate care programs.

The development of a direct measure to demonstrate the cost effectiveness of home health attendant or hospice care as compared to acute care hospitalization was not feasible. This was due to the impact which various home health and other alternative care programs were having upon the number of hospitalizations and length of hospital stays being experienced by persons with AIDS or ARC. Consequently, indirect measures were formulated based upon the following assumptions:

1. The distribution of the days of hospitalization experienced by persons with AIDS is bipolar That is, high at diagnosis and during the terminal phase of the disease and at a lower level during the disease progression.

2. A reduction in the number of hospitalizations through use of home health care would reduce overall cost of care.

3. A reduction in the total number of days of hospitalization due to home health care would reduce total cost of care.

4. A high level of client satisfaction of would demonstrate effectiveness related to quality of life issues.

5. High levels of physician satisfaction would demonstrate effectiveness and quality of care.

6. Data could be stratified and comparisons drawn between and among subgroups of the sample.

7. Data could be reported in terms of units of service, including volunteer services, to provide a basis for determining total costs and allow for generalization beyond Los Angeles.
8. Home health attendant or hospice care would allow for a less

restrictive environment than would hospitalization, thereby, allowing for greater independence and a wider range of services .

The scope of the study became much wider than just a comparison of the costs of home care and acute care hospitalization. It became a descriptive study of a system of care which rests upon the concept to total care, including acute care hospitalization. The design which emerged became an analysis of units of service (and costs) for the provision of a comprehensive care program for persons with AIDS or ARC which can be compared to the predetermined cost figures or units of service for persons with AIDS or ARC who receive their care primarily through acute care hospital facilities. (It should be noted, however, that while such comparisons may be meaningful for the purpose of determining the most cost effective approach to providing care for persons with AIDS or ARC, there are other factors which are not easily measured. These include the effects of independence, emotional and spiritual growth, and being in proximity to loved ones within familiar surroundings On the other hand, the feeling of security experienced as a result of being in a hospital where immediate acute care is available is also difficult to measure.)

Methods

This project was an attempt to collect data specific to units of service provided through a community based home health attendant or hospice program. The population was defined as all persons within Los Angeles County diagnosed with AIDS or ARC at the early acute (70) functional level, or lower, as measured by the Karnofsky Scale. Subjects were targeted through publicity to 7,000 medical doctors in Los Angeles County, hospitals, AIDS service organization clients, and the media, including outreach to minority communities.

The Karnofsky Performance Status Scale scores were provided by the primary physicians of prospective subjects through signing a certificate of eligibility. These certificates were sent to the physicians at the request of the subject or through direct physician request. All patients signed informed consents and medical information releases prior to participation in the study. Client confidentiality was maintained through the assignment of code numbers for identification purposes and keeping client records and reports in locked files. Once certificates of eligibility were received from the physicians and a diagnosis of AIDS or ARC was verified, a prospective subject pool was established. Receipt of the certificate of eligibility was accepted as an application to participate in the study. Certificates were accepted through November 1986, at which time the study was closed.

The sample was drawn from the pool of applicants who met eligibility criteria on a first come, first served basis with the exception of women, children and minority applicants. All women, children, blacks, Asians and American Indians who made application and met Karnofsky criteria were accepted. All Hispanics who made application through September 1987, and met Karnofsky criteria were accepted. After September 1987, applicants of Hispanic origin were considered with all other applicants.

Upon identification of a prospective study participant, one of the case managers would complete a client intake interview. This included the standard AIDS Project Los Angeles client registration and psychosocial needs assessment. The Initial Client Entry Form, required by the study, provided the baseline case report of demographic and health data. An individual care plan was developed and presented to the Project Director. At that time a study case number was assigned and the client officially enrolled. If it was determined through the intake procedure that home health services were needed, a service provider was notified and an initial nursing evaluation completed. After the nursing evaluation was completed, services were initiated.

Each case was reevaluated on a bi-weekly basis and reviewed on a weekly basis at the weekly case management conference. The services provided included home health attendant care, intermittent skilled nursing, emotional support, food, insurance counseling, a buddy, transportation, and the development of a hospice care plan and bereavement counseling as appropriate. The care plan and services were accessed through the case managers.

Quality control was maintained by the Project Director through spot checks and bi-weekly phone contacts with all clients. Additionally, each client was requested to complete a bi-weekly evaluation form. All clients receiving home health services were contacted weekly by the case manager and nursing representatives of the service providers participated in the weekly case management meetings. Data was collected through written reports from all parties providing services and by review of all billing associated with each case. Client satisfaction data was collected by phone and in writing on a bi-weekly basis. Physician satisfaction reports were collected when a client expired.

Clients were afforded the opportunity to withdraw from the project at any time. Should a client elect to withdraw from the study, he was was still entitled to any services normally provided to any other client of AIDS Project Los Angeles. Two clients did withdraw during the study. One client who withdrew moved out of the state; another, who was a hemophiliac, withdrew because he "did not want to be associated with a 'homosexual study'."

Types of Data Collected

The data collected included:

1. Demographic
2. Biographic
3. Units of Service by type
4. Cost of services where applicable
5. Client satisfaction
6. Physician Satisfaction

Data was stratified to allow for analysis by subgroup including living condition, mode of transmission, sex, ethnicity, insurance, and diagnosis.

Limitations of the Study

The limitations of the study center principally around five points:

1. Subjects were either self selected or physician selected.
2. Only subjects at 70 or below on the Karnofsky functional scale were accepted.
3. Data are specific to Los Angeles County.
4. Low enrollment from the black community.
5. Low enrollment of IV drug users.

The difficulty in making contact with members of the population from which the sample was to be drawn required that potential subjects be reached through a secondary source. Letters to physicians, hospitals, media and AIDS service organizations alerted potential subjects of the existence of the study. The referral sources became primarily physicians and the subjects themselves. Consequently, it is highly likely that the subjects solicited represent a disproportionate number of individuals without resources adequate to meet their needs. This may account for the high percentage (50.4) who relied upon Medi-Cal, Medicare, or solely upon the project (APLA) for home health care.

The enrollment of subjects at Stage II on the Karnofsky scale (70 or below) resulted in clients being on the study for a relatively short period of time (mean 130 days). It is highly probable that, if subjects had been enrolled at diagnosis (Stage I of the Karnofsky scale), the number of days of hospitalization prior to entering the study would have been reduced.

The population from which the sample was drawn was limited to Los Angeles County. It is impossible to say if persons with AIDS or ARC in other sections of the state demonstrate the same characteristics or need. Therefore, any generalization beyond Los Angeles County must be done with great reservation, if at all.

The limited numbers of representatives from the black community (4%) may reflect the hesitancy of this minority group to access services provided by an agency primarily associated with the white gay community. While a concerted effort was made to reach this population, it met with limited success.

The intravenous drug user population was also not well represented within the study. The primary difficulties encountered in attempts to reach this population were the small number of diagnosed cases within Los Angeles County and that the majority of the Stage IV drug users appear to be members of the minority community who are hesitant to seek services from an AIDS organization which is viewed as primarily serving the gay community.

Results

The AIDS Project Los Angeles Home Health Attendant or Hospice Care Pilot Project enrolled 137 subjects between April 1, 1986 and May 31, 1987. Of the subjects enrolled, 122 were diagnosed with Acquired Immune Deficiency

Syndrome (AIDS) and 15 were diagnosed with an AIDS Related Condition (ARC). Two subjects withdrew from the course of the study; one subject moved from the State, and one subject is a hemophiliac and did not wish to be associated with what he perceived as a "gay" study. At the conclusion of the study year, 99 subjects had expired and 36 remained alive.

The results of the Home Health Attendant or Hospice Care Pilot Study, conducted by AIDS Project Los Angeles are presented in Tables 1 through Table 9, Distribution of Subject Characteristics, represents demographic and biographic descriptions of the sample (N=137). Almost 88% of the sample identified themselves as homosexual or bisexual. The remaining risk categories account for approximately 6% of the group. No known risk category was reported for 6.6% of the sample. No heterosexual IV drug users were represented in the sample.

The sample was predominantly Caucasian, other than Hispanic (72.99%). Hispanics represented approximately 20% of the sample, 4.4% were black and 2.2% were Native American. The sexual orientation of the sample was predominantly homosexual and bisexual (87.6%). Of the remainder, 11% were heterosexual; this figure includes the two children who were on the study.

Upon entry to the study, approximately 89% of the subjects had a diagnosis of AIDS. The remaining clients (10.95%) had a diagnosis of ARC. No clients were entered into the study without a physician certification of one of these two diagnoses. Additionally, admission into the study required that each subject be assessed at 70 or less (Stage II, Early Chronic) on the Karnofsky Scale. The Karnofsky Scale is a measure of functional level originally developed for use with cancer patients and is widely used as a metric in AIDS related research. At entry to the study, 61.3% of the clients were ambulatory, 27.7% were ambulatory with assistance, and 10.9% were bedridden.

Of the 137 clients, 64 (46.7%) lived alone. Only 29.2 lived with lovers or spouses, 13% lived with blood relatives and 9.5% lived with friends. Only one individual had an unstable living situation and he was eventually placed in a congregate living situation.

The sample included only two children. Both were the offspring of mothers who were HIV positive. In one case, the mother was also a part of the sample. It is interesting to note that there were no clients on the study in the 10 to 19 year old age range. The majority of the clients served (almost 70%) were between 30 and 49 years of age. The mean age for the sample was 39.64 years and ranged from 2 years to 68 years of age.

The sample was predominantly male. Of the total 137 subjects served by the Pilot Project, only 4 were female, with one of the females being a child.

The number of days subjects were on the study ranged from 2 to 353. The majority (73.0%) were on the study for more than 90 days. Prior to entering the study clients averaged 38.02 days of hospitalization. The mean number of days hospitalized while on the study was 10.2 days. Of the total 137 subjects, 70 (51.1%) were never hospitalized once they were enrolled into the study. The mean number of hospital admissions per subject while on the study was 0.72. However, this reflects multiple admissions for 24 of the subjects and no admissions to the hospital for 70 of the subjects.

Table 2, Hours of Service Provided, reflects the units of service provided to the 137 subjects of the Home Health Attendant or Hospice Care Pilot Project, conducted by AIDS Project Los Angeles. These services were provided between April 1, 1986 and May 31, 1987.

Attendant care was defined as both personal and practical support services. All attendants received specific training in the care of persons with AIDS or ARC from the agencies with whom they were employed. The training included precautions to be exercised as well as psycho-social variables to be considered while caring for persons with HIV infection. The duties of the attendant included light housekeeping, meal preparation, assistance with dressing, bathing, toileting, and reminding clients to take medications, as appropriate. Attendants also accompanied subjects to medical appointments and provided other support functions as were deemed appropriate. The attendants were provided written care plans to follow and were monitored and supervised by skilled nursing staff.

A total of 59,926.69 hours of attendant care were provided to the 137 subjects of the study. The mean number of hours of attendant care provided was 437.42 hours, with an average of 4.18 hours of service per day, per subject. Each attendant was monitored on at least a biweekly basis, through on-site visitation by a nurse evaluator. Bi-weekly reports were submitted to the Project Director by the subjects and biweekly telephone contacts were made by the Director's office to insure client satisfaction.

Home nursing was minimized through the extensive use of Attendant Care. Skilled nursing home visits were combined with attendant supervision on a biweekly basis. These nursing visits were primarily for the purpose of evaluation of the current status of the subject and supervision of the attendant. They were not reported separately from the attendant care and are not included in the Home Nursing units of service. Intermittent skilled was available on an "as required" basis. A total of 1,266.09 hours of skilled nursing was provided. The mean number of nursing hours provided per subject was 9.24 hours.

Mental health services were provided in two ways. A licensed clinical social worker provided input at the weekly case conference meetings to provide guidance and support for the providers of services. Mental health personnel were also available to see subjects, upon request. Shanti, which provided the emotional support personnel, also provided a mental health professional who provided supervision and guidance to the professional who provided supervision and guidance to the emotional support volunteers. A total of 2,511 hours of professional mental health services and 2,591 hours of emotional support were provided. These services included provision of an emotional support volunteer to all subjects who requested one and bereavement counseling for families and significant others upon request.

Volunteer services included everything from driving clients who were not receiving attendant care to medical appointments to the feeding of pets while subjects were hospitalized. The total number of hours of volunteer services provided were 4,110.75, or 30.01 hours per subject.

The case manager maintained contact with each subject through face-to-face contact, telephone contact with the client and the significant others of the client, providing access to all available services and generally serving as advocate for the subject. Case managers attended all case conferences and were the primary "gate keepers" for services and cost containment. A total of 887.34 hours of direct contact and case conferencing were provided (6.48 hours per subject). Insurance counseling was also provided at the rate of .71 hours per client. This service was provided in an effort to insure that each subject was provided assistance in the maintenance of insurance coverage in the negotiation for services.

The mean number of hours of services provided each client was 521.1 hours. This ranged from 2.86 hours to 4,139.45 hours, depending upon the the unique needs of each subject. The mean number of hours per day, per subject, was 4.93 hours of service.

Table 3, Cost of Services Provided, includes all "pay for service" categories. These costs include those costs which were paid through third party payors as well as funds expended through the Pilot Project.

The total costs for Attendant Care services was $621,549.15. The mean per subject cost was $4,536.86 for the 137 subjects on the study. This represents the average of $43.85 per day, per subject. Home Nursing costs totaled $234,309.02. The mean total cost per subject was $1,710.29 or $12.62 per subject, per day. This figure is inflated due to an insurance payment of $126,658.17 for home nursing services provided for one subject.

The total expenditure for Mental Health services was $32.492.34 or $232.17 per subject. Case Management, including Insurance Counseling totaled $11,727 or $85.60 per subject.

The mean costs per client for the approximately 130 days of service provided, including all services for which payment was made, was $6,569.93. The total amount expended was $900,079.88. The average cost per subject, per day, was $59.71.

A further breakdown of services provided for clients who had expired during the course of the study (N=99) and those still active at the conclusion of the study year (N=36) are included in Tables 4 and 5.

Table 6 represents the levels of satisfaction with services being provided, as evaluated by subjects, across areas. These reports were collected on a bi-weekly basis, in writing, from the subjects. The subjects received the questionnaire through the mail with a self-addressed, stamped return envelope. They were requested to check appropriate scores, from 1 to 5 and return the form to the Director's office. When the subject was not able to complete the form, a significant other was requested to complete it for him at his direction. When this was not possible, no report was submitted.

Table 7 represents Physician Satisfaction with the services provided during the course of study participation by their patients. The Physician Satisfaction reports were completed after the patient expired and includes ratings on a 3 point scale across 12 areas.

Tables 8 and 9 represent a break out of costs among private insurance payments, Medi-Cal, Medi-Care, and no insurance. Comparisons among the subgroups is interesting. These differences appear to reflect systemic differences rather than variations in need. Medi-Cal patients, as an example, are most frequently provided services in Los Angeles, through public hospitals which are teaching hospitals, while the majority of private insurance patients are provided services through private facilities.

Conclusions

The Home Health Attendant or Hospice Care Pilot Study was an attempt to collect and analyze data specific to units of service required, and the cost of caring for persons with AIDS or ARC in a home setting. The study was designed to demonstrate the cost effectiveness of home health attendant or hospice care as compared to the alternative of acute care hospitalization. Assumptions basic to the study were that:

1. The bi-polar distribution of required days of hospitalization during the course of the disease could be broken in upon. That is, there would be no significant increase in the number of days

of hospitalization just prior to death and that a decrease in total days of hospitalization would be demonstrated.

2. An overall reduction in hospital admissions would be reported.

3. Subjects would demonstrate a high level of satisfaction with home health or hospice care.

4. Physicians would demonstrate a high level of satisfaction with homehealth or hospice care.

Subjects reported a 38.02 mean number of days of hospitalization prior to entering the study. This figure is somewhat inflated due to the 13 subjects who reported 90 to 200 days of prior hospitalization. A review of the records of these subjects revealed that the majority of the days of hospitalization were the result of inadequate or no home support systems. The mean number of days of hospitalization reported by this subgroup was 118.56 days prior to entering the study and 18.33 days after entering the study. With these subjects excluded the mean number of days of hospitalization prior to entering the study for the remaining 123 subjects is 29.52 days. The mean number of days of hospitalization for all 137 subjects while on the study is 10.2 days.

The average lifetime number of days of hospitalization for persons with AIDS is reported by the Southern California Hospital Council (June 30, 1986), as approximately 52 days. It appears that with adequate home health attendant or hospice care the total number of days of hospitalization during the lifetime of the patient can be reduced significantly.

Admission to the hospital while on the study was reported as .72, with 70 individual reporting no admissions. Of the 99 who expired during the course of the project, 43 were never re-admitted to the hospital. This is particularly interesting considering that only 8 had not been hospitalized prior to entry onto the study.

Client satisfaction was very high throughout the study. An overall rating of 3.77 on a 5 point Likert-type scale was reported. They would appear to indicate a high level of subject satisfaction.

Comparatively, physician satisfaction was even higher than that reported by subjects. On a 3 point Likert-type scale, physicians reported a 2.68 level of satisfaction.

Discussions

The Home Health Attendant or Hospice Care Pilot Study appears to indicate both a high level of cost effectiveness and subject/physician satisfaction. The results indicate the very broad range of needs among the subjects. These needs are reflected in comparative costs. Service demands are heavy and some needs are not being met in the most effective or efficient manner.

The hospital costs for providing services to persons with AIDS or ARC appear to be inflated due to:

1. Lack of availability of adequate home health care.
2. Lack of sufficient mental health facilities to provide services to persons with AIDS or ARC and their significant others.
3. Lack of housing support.
4. Overcrowding of public hospitals.

Each of these factors contribute to increased cost of care. When adequate home health services are not available, individuals tend to spend a longer period of time in acute care units. In several cases subjects experienced extended hospitalizations due to suicidal ideation. Some subjects had no place to go upon release from the hospital, consequently they remained in the hospital until housing could be arranged. The overcrowding and understaffing of some facilities resulted in delays in testing and treatment and hospital stays were extended. The increased demands upon the health service system, due to the AIDS epidemic, has, and is, creating stress. The system has not caught up to the demand for services and has created delays in some services, thus increasing costs.

Recommendations

Specific recommendations to assist to further reduce the cost of care for persons with AIDS or ARC:

1. Initiate an adult foster care program. That is, reimburse families or individuals for opening their homes to Persons with AIDS or ARC (they would be required to meet licensing requirement similar to those required of foster homes for children).

   This would provide a supportive environment in which home health care services could be provided.

2. Establish Adult Day Care Centers for persons with AIDS which would allow for some health and mental health care as well as socialization and client education. This would allow family members or significant others, to maintain full time employment knowing that their loved one is being well cared for.

3. Provide a broader range of mental health services for persons affected by AIDS. This should include access to residential facilities for those experiencing neurological dysfunctions, dementia, or severe emotional disturbance.

4. Provide comprehensive case management through an interdisciplinary case management team.

This study is only a first step toward defining need, levels of care needed and the units of service required to meet those needs. Further study is required to validate the current findings and further define what services are required, the extent they are required, and the cost of the provisions of such services.

The person with AIDS or ARC appears to prefer living and dying at home in the surrounding with which he is most familiar, near those he loves. If quality of life is to be preserved and furthered, it appears essential that the wishes of the client be considered. If the wishes of the client are to be met, it appears essential that the issues, needs, and approaches to meeting those needs be studied further and in greater depth.

AIDS PROJECT LOS ANGELES

Home Health Attendant or Hospice Care Pilot Study of
April 1, 1986 to May 31, 1987

Table 1 - DISTRIBUTION OF SUBJECT CHARACTERISTICS

(All percentages are rounded to nearest 10th;
tables may exceed or be less than 100%.)
(N = 137)

RISK CATEGORY

Category	Frequency	Percent
Homosexual/Bisexual	120	87.6
Homosexual/IV Drug User	1	0.7
Hemophiliac	1	0.7
Heterosexual	3	2.2
Transfusion	3	2.2
Other/None of the above	9	6.6

ETHNICITY

Category	Frequency	Percent
Black	6	4.4
Hispanic	27	19.7
Native American	3	2.2
White	100	73.0
Asian/Pacific Islander	0	0.0
Other	1	0.7

SEXUAL ORIENTATION

Category	Frequency	Percent
Homosexual	109	79.6
Heterosexual	15	10.9
Bisexual	13	9.5

DIAGNOSIS

Category	Frequency	Percent
ARC	15	10.9
AIDS	122	89.1

FUNCTIONAL CAPACITY
(at time of entry to study)

Category	Frequency	Percent
Ambulatory	84	61.3
Ambulatory, with assistance	38	27.7
Bedridden	15	10.9

KARNOFSKY STAGE
(at entry to study)

Category	Frequency	Percent
Stage I (Diagnosis)	0	0.0
Stage II (Early Chronic)	61	44.5
Stage III (Late Chronic)	66	48.55
Stage IV (Critical)	10	7.3

LIVING ARRANGEMENTS
(at time of entry to study)

Category	Frequency	Percent
Lover/ Spouse	40	29.2
Blood Relatives	19	13.9
Friends	13	9.5
Alone	64	46.7
Unstable	1	0.7

AGE

Category	Frequency	Percent
0 to 9 years	2	1.5
10 to 19 years	0	0.0
20 to 29 years	9	6.6
30 to 39 years	62	45.3
40 to 49 years	33	24.1
50 years & over	31	22.6

MEAN age of the Los Angeles sample = 39.64 years

SEX

Category	Frequency	Percent
Male	133	97.1
Female	4	2.9

NUMBER OF CLIENT DAYS ON STUDY

Category	Frequency	Percent
1 to 30	28	20.4
31 to 90	36	26.3
91 to 180	28	20.4
181 to 270	28	20.4
271 to 400	17	12.4

Mean = 129.78
Range = 2 to 353.00
Total = 17,779

NUMBER OF CLIENT DAYS IN HOSPITAL PRIOR TO STUDY ENTRY

Category	Frequency	Percent
0 to 20	52	38.0
21 to 40	31	22.6
41 to 60	29	21.2
61 to 90	16	11.7
91 to 200	9	6.6

MEAN number of days in hospital prior to study entry = 38.02
Range= 0 to 200
Total= 5208

NUMBER OF CLIENT DAYS IN HOSPITAL
WHILE ON THE STUDY

Category	Frequency	Percent
none	70	51.1
1 to 10	20	14.7
11 to 20	21	15.3
21 to 35	15	10.8
36 to 50	6	4.4
51 to 69	5	3.5

MEAN days in hospital while on study = 10.20
Range = 0 to 69
Total days in hospital while on study = 1396

NUMBER OF CLIENT ADMISSIONS TO
HOSPITAL WHILE ON THE STUDY

Category	Frequency	Percent
none	70	51.1
1	43	31.4
2	17	12.4
3	4	2.9
4	1	0.7
5	0	0.0
6	2	1.5

MEAN number hospital admissions while on study = 0.72
Range = 0 to 6
Total number of hospital admissions while on study = 99

AIDS PROJECT LOS ANGELES

Home Health Attendant or Hospice Care Pilot Study of April 1, 1986 to May 31, 1987

Table 2 - HOURS OF SERVICE PROVIDED

(N = 137)

Attendant Care

Mean ....437.42 hours
Range ....0 to 4,096.00 hours
Total ....59, 926.69 hours

Average of 4.18 Attendant Care Hours, per client, per day

Clients receiving Attendant Care = 104
Clients not receiving Attendant Care = 33

Home Nursing Care

Mean .... 9.24 hours
Range .... 0 to 270.50 hours
Total .... 1,266.09 hours

Average of 0.12 Home Nursing Care Hours, per client, per day

Clients receiving Home Nursing Care = 104
Clients not receiving Home Nursing Care = 33

Table 2
Page 2

Mental Health Care

Mean .... 18.33 hours
Range .... 0.60 to 49.80 hours
Total .... 2511.00 hours

Clients receiving Mental Health Services = 137
Clients not receiving Mental Health Services = 0

Emotional Support

Mean .... 18.82 hours
Range .... 0 to 251.00 hours
Total .... 2,591.30 hours

Clients receiving Emotional Support = 48
Clients not receiving Emotional Support = 89

Volunteer Services

Mean .... 30.01 hours
Range .... 0 to 562.50 hours
Total .... 4,110.75 hours

Clients receiving Volunteer Services = 58
Clients not receiving Volunteer Services = 79

Case Management

Mean .... 6.48 hours
Range .... 1.78 to 59.32 hours
Total .... 887.34 hours

Clients receiving Case Management = 137
Clients not receiving Case Management = 0

Insurance Counseling

Mean .... 0.71 hours
Range .... 0 to 7.5 hours
Total .... 97.50 hours

Clients receiving Insurance Counseling = 49
Clients not receiving Insurance Counseling = 79

TOTAL HOURS OF SERVICE PROVIDED
(all categories combined)

Mean number of hours per each client 521.10

Range .... 2.86 to 4,139.45

Total hours of service provided 71,390.67

Mean number of hours per client, per day 4.93

AIDS PROJECT LOS ANGELES

Home Health Attendant or Hospice Care Pilot Study of April 1, 1986 to May 31, 1987

Table 3 - COST OF SERVICES PROVIDED

(N = 137)

Attendant Care

Mean	$ 4,536.86
Range	$ 0 to 37,139.76
Total	$ 621,549.15

Average of $ 43.85 Attendant Care cost, per client, per day

Home Nursing

Mean	$ 1,710.29
Range	$ 0 to 126,658.17
Total	$ 234,309.02

Average of $ 12.62 Home Nursing cost, per client, per day

Mental Health Services

Mean	$ 232.17
Range	$ 7.76 to 644.41
Total	$ 32,492.34

Table 3
Page 2

Case Management

Mean	$ 76.82
Range	$ 21.11 to 703.54
Total	$ 10,523.85

Insurance Counseling

Mean	$ 8.78
Range	$ 0 to 92.55
Total	$ 1,203.15

Case Management & Insurance Counseling
(Combined)

Mean	$ 85.60
Range	$ 21.35 to 703.54
Total	$ 11,727.00

TOTAL COST OF SERVICES
(includes attendant care, home nursing, mental health services, insurance counseling, and case management costs)

Mean	$ 6,569.93
Range	$ 34.57 to 127,216.79
Total	$ 900,079.88

. Average of $ 59.71 for all "pay for service" categories combined; per client, per day

AIDS PROJECT LOS ANGELES

Home Health Attendant or Hospice Care Pilot Study of April 1, 1986 to May 31, 1987

Table 4 - UNITS OF SERVICES PROVIDED FOR EXPIRED CLIENTS

(N = 99)

Days on Study

Mean	97.44 days
Range	2 to 238 days
Total	9647 days

Days in Hospital Prior to Entry to Pilot Study

Mean	40.55 days
Range	0 to 140 days
Total	4014 days

Clients hospitalized prior to study=91

Clients not hospitalized prior to study=8

Days in Hospital While on Pilot Study

Mean	11.57 days
Range	0 to 69 days
Total	1145 days

Clients hospitalized on study=56

Clients not hospitalized while on study=43

Admissions to Hospital While on Pilot Study

Mean .... 0.82 admissions

Range .... 2 to 6 admissions

Total .... 81 admissions

Admitted to hospital=56

No admissions=43

Attendant Care

Mean .... 464.03 hours

Range .... 2 to 4096.00 hours

Total .... 45,938.62 hours

Average of 4.97 Attendant Care Hours
per client, per day

Clients receiving Attendant Care = 78
Clients not receiving Attendant Care = 21

Home Nursing Care

Mean .... 8.93 hours

Range .... 0 to 154.25 hours

Total .... 884.26 hours

Average of 0.14 Home Nursing Care Hours
per client, per day

Clients receiving Home Nursing Care = 55
Clients not receiving Attendant Care = 44

Insurance Counseling

Mean .... 0.67 hours

Range .... 0 to 7.25 hours

Total .... 66.25 hours

Clients receiving Insurance Counseling = 36
Clients not receiving Insurance Counseling = 63

Case Management

Mean .... 6.50 hours

Range .... 1.78 to 59.32 hours

Total .... 643.79 hours

Clients receiving Case Management = 99
Clients not receiving Case Management = 0

Mental Health

Mean .... 13.74 hours

Range .... 0.60 to 46.20 hours

Total .... 1360.60 hours

Clients receiving Mental Health = 99
Clients not receiving Mental Health = 0

Table 4
Page 4

Emotional Support

Mean	16.12 hours
Range	0 to 189.85 hours
Total	1595.55 hours

Clients receiving Emotional Support = 35
Clients not receiving Emotional Support = 64

Volunteer Services

Mean	31.71 hours
Range	0 to 562.50 hours
Total	3139.25 hours

Clients receiving Volunteer Services = 99
Clients not receiving Volunteer Services = 51

TOTAL HOURS OF SERVICE PROVIDED
(All categories combined)

Mean number of hours per each client	541.70
Range	2.86 to 4139.45
Total hours of service provided	53,628.32
Mean number of hours, per client, per day	5.80

AIDS PROJECT LOS ANGELES

Home Health Attendant or Hospice Care Pilot Study of April 1, 1986 to May 31, 1987

Table 5 - UNITS OF SERVICES PROVIDED FOR ACTIVE CLIENTS ON MAY 31, 1987

(N = 36)
(Two subjects voluntarily withdrew from study.)

Days on Study

Mean	214.00 days
Range	12 to 353 days
Total	8132 days

Days in Hospital Prior to Entry to Pilot Study

Mean	43.42 days
Range	0 to 200 days
Total	1194 days

Clients hospitalized prior to study=29

Clients not hospitalized prior to study=9

Days in Hospital While on Pilot Study

Mean	6.61 days
Range	0 to 49 days
Total	125 days

Clients hospitalized while on study=11

Clients not hospitalized on study=27

Admissions to Hospital While on Pilot Study

Mean .... 0.47 admissions

Range .... 0 to 3 admissions

Total .... 38 admissions

Admitted to hospital=11

No admissions to hospital=27

Attendant Care

Mean .... 368.11 hours

Range .... 0 to 3171.75 hours

Total .... 13,988.07 hours

Average of 2.13 Attendant Care Hours
per client, per day

Clients receiving Attendant Care = 26
Clients not receiving Attendant Care = 12

Home Nursing Care

Mean .... 10.05 hours

Range .... 0 to 270.50 hours

Total .... 881.83 hours

Average of 0.05 Home Nursing Care Hours
per client, per day

Clients receiving Home Nursing Care = 12
Clients not receiving Attendant Care = 26

Insurance Counseling

Mean .... 0.82 hours

Range .... 0 to 7.50 hours

Total .... 31.25 hours

Clients receiving Insurance Counseling = 13
Clients not receiving Insurance Counseling = 25

Case Management

Mean .... 6.41 hours

Range .... 1.89 to 32.81 hours

Total .... 243.75 hours

Clients receiving Case Management = 38
Clients not receiving Case Management = 0

Mental Health

Mean .... 30.27 hours

Range .... 1.80 to 49.80 hours

Total .... 1150.40 hours

Clients receiving Mental Health = 38
Clients not receiving Mental Health = 0

Emotional Support

Mean .... 26.20 hours

Range .... 0 to 251.00 hours

Total .... 995.75 hours

Clients receiving Emotional Support = 13
Clients not receiving Emotional Support = 25

Volunteer Services

Mean .... 25.57 hours

Range .... 0 to 193.00 hours

Total .... 971.50 hours

Clients receiving Volunteer Services = 10
Clients not receiving Volunteer Services = 28

TOTAL HOURS OF SERVICE PROVIDED
(All categories combined)

Mean number of hours per each client 467.44

Range .... 15.06 to 3377.68

Total hours of service provided 17,762.55

Mean number of hours, per client, per day .. 2.66

AIDS PROJECT LOS ANGELES

Home Health Attendant or Hospice Care Pilot Study of April 1, 1986 to May 31, 1987

Table 6 - UNITS OF SERVICE PROVIDED FOR CLIENTS WITH PRIVATE INSURANCE, MEDI-CAL & MEDICARE, AND NO INSURANCE

(All percentages are rounded to nearest 10th;
tables may exceed or be less than 100%.)
(N = 137)

Distribution of Cases

Category	Frequency	Percent
Private Insurance	68	49.6
Medi-Cal	52	38.0
Medicare	6	4.4
No Medical coverage	11	8.0

Days on Study

	Private Insurance	MediCal	Medicare	No coverage
Mean	114.84	136.00	153.83	162.55
Range	5 to 353	2 to 335	34 to 344	8 to 327
Total	7809	7259	923	1788

Days in Hospital Prior to Entry to Pilot Study

	Private Insurance	MediCal	Medicare	No coverage
Mean	39.02	39.62	41.00	22.64
Range	0 to 200	0 to 105	8 to 105	0 to 140
Total	2653	2060	246	249
With Days Prior	61	46	6	7
No Days Prior	7	6	0	4

Days in Hospital While on Pilot Study

	Private Insurance	MediCal	Medicare	No coverage
Mean	8.84	10.77	28.82	5.64
Range	0 to 54	0 to 66	0 to 69	0 to 42
Total	601	560	173	62
Hospitalized	31	29	4	3
Not Hospitalized	37	23	2	8

Admissions to Hospital While on Pilot Study

	Private Insurance	MediCal	Medicare	No coverage
Mean	.68	.904	1	.46
Range	0 to 6	0 to 6	0 to 2	0 to 2
Total	46	47	6	5
Admissions	31	29	4	3
No Admissions	37	23	2	8

ATTENDANT CARE

Private Insurance (N = 68)

Mean .... 397.51 hours

Range .... 0 to 4096.00 hours

Total .... 27,030.78 hours

Clients receiving Attendent Care = 51

Clients not receiving Attendent Care = 17

Medi-Cal (N = 52)

Mean .... 472.64 hours

Range .... 0 to 3449.75 hours

Total .... 24577.21 hours

Clients receiving Attendent Care = 40

Clients not receiving Attendent Care=12

Medi-Care (N = 6)

Mean .... 569.50 hours

Range .... 0 to 2170.00 hours

Total .... 3417.00 hours

Clients receiving Attendent Care = 5

Clients not receiving Attendent Care = 1

No Coverage (N = 11)

Mean .... 445.61 hours

Range .... 0 to 2927.95 hours

Total .... 4901.70 hours

Clients receiving Attendent Care = 8

Clients not receiving Attendent Care = 3

HOME NURSING CARE

Private Insurance (N = 68)

Mean .... 10.67 hours

Range .... 0 to 270.50 hours

Total .... 725.29 hours

Clients receiving Home Nursing Care = 31

Clients not receiving Home Nursing Care = 37

Medi-Cal (N = 52)

Mean .... 6.82 hours

Range .... 0 to 82 hours

Total .... 354.36 hours

Clients receiving Home Nursing Care = 29

Clients not receiving Home Nursing Care = 23

Medi-Care (N = 6)

Mean .... 11.46 hours

Range .... 0 to 61.02 hours

Total .... 68.77 hours

Clients receiving Home Nursing Care = 3

Clients not receiving Home Nursing Care = 3

No Coverage (N = 11)

Mean .... 10.70 hours

Range .... 0 to 100.00 hours

Total .... 117.67 hours

Clients receiving Home Nursing Care = 4

Clients not receiving Home Nursing Care = 7

CASE MANAGEMENT

Private Insurance (N = 68)

Mean .... 7.78 hours

Range .... 1.8 to 37.68 hours

Total .... 529.08 hours

Medi-Cal (N = 52)

Mean .... 6.32 hours

Range .... 1.86 to 24.80 hours

Total .... 228.38 hours

Medi-Care (N = 6)

Mean .... 3.77 hours

Range .... 1.92 to 5.88 hours

Total .... 22.62 hours

No Coverage (N = 11)

Mean .... 9.54 hours

Range .... 1.89 to 59.32 hours

Total .... 104.96 hours

* All Clients received Case Management (N = 137)

AIDS PROJECT LOS ANGELES

Home Health Attendant or Hospice Care Pilot Study of
April 1, 1986 to May 31, 1987

Table 7 - COST OF SERVICES PROVIDED FOR CLIENTS WITH PRIVATE INSURANCE, MEDI-CAL & MEDICARE, AND NO INSURANCE

(All percentages are rounded to nearest 10th;
tables may exceed or be less than 100%.)
(N = 137)

Distribution of Cases

Category	Frequency	Percent
Private Insurance	68	49.6
Medi-Cal	52	38.0
Medicare	6	4.4
No Medical coverage	11	8.0

Attendant Care

	Private Insurance	MediCal	Medicare	No coverage
Mean	3989.87	5029.77	6072.30	4750.56
Range	0 to 36690.80	0 to 37139.76	0 to 23043.00	0 to 31421.50
Total	271311.18	261548.04	36433.80	522256.13

	Home Nursing Care Private Insurance	MediCal	Medicare	No coverage
Mean	2975.24	445.85	730.24	402.48
Range	0 to 126658.17	0 to 3085.50	0 to 3867.44	0 to 3147.50
Total	202316.35	23183.99	4381.44	4427.24

	Case Management Private Insurance	MediCal	Medicare	No coverage
Mean	92.86	75.02	44.71	113.24
Range	21.35 to 447.01	22.06 to 294.13	22.77 to 69.74	22.42 to 703.54
Total	6314.25	3901.19	268.27	1245.67

AIDS PROJECT LOS ANGELES

Home Health Attendant or Hospice Care Pilot Study of April 1, 1986 to May 31, 1987

Table 8 - CLIENT SATISFACTION RATINGS

APLA (N = 137)

Ratings are based on a 5 point Likert-type scale:

1 = Does not satisfy my basic needs
2 = Satisfies some of my basic needs, but not all
3 = Satisfies all my basic needs
4 = Satisfies more than my basic needs
5 = Completely satisfies me in every way

1. Attendant Care ratings

    Mean = 3.54
    Range 1 to 5
    Number of Clients reporting = 80
    Number of Clients not reporting = 57

2. Home Nursing Care ratings

    Mean = 3.79
    Range 1 to 5
    Number of Clients reporting = 73
    Number of Clients not reporting = 64

3. Emotional Health Support (Shanti) ratings

    Mean = 3.49
    Range 1 to 5
    Number of Clients Reporting = 70
    Number of Clients Not Reporting = 67

4. Insurance Counseling ratings

    Mean = 3.18
    Range 1 to 5
    Number of Clients reporting = 45
    Number of Clients not reporting = 92

5. Case Management ratings

   Mean = 3.74
   Range 1 to 5
   Number of Clients reporting = 85
   Number of Clients not reporting = 52

6. Emergency Shelter, Transportation, and Food Subsidy Program ratings

   Mean = 3.46
   Range 1 to 5
   Number of Clients reporting = 65
   Number of Clients not reporting = 72

7. Overall rating of the services provided

   Mean = 3.77
   Range 1 to 5
   Number of Clients Reporting = 89
   Number of Clients Not Reporting = 48

AIDS PROJECT LOS ANGELES

Home Health Attendant or Hospice Care Pilot Study of April 1, 1986 to May 31, 1987

Table 9 - PHYSICIAN SATISFACTION RATINGS

APLA (N = 137)

Ratings are based on a 3 point Likert-type scale:

1 = Does not satisfy my patient's needs.
2 = Satisfies some of my patient's needs, but not all.
3 = Satisfies all my patient's needs.

1. Attendant Care

    Mean = 2.61
    Range 1 to 3
    Number of client care ratings returned = 63
    Number of client care ratings not available = 74

2. Home Nursing Care

    Mean = 2.48
    Range 1 to 3
    Number of client care ratings returned = 54
    Number of client care ratings not available = 83

3. Pain Management

    Mean = 2.51
    Range = 1 to 3
    Number of client care ratings returned = 55
    Number of client care ratings not available = 82

4. IV Therapy

    Mean = 2.51
    Range = 1 to 3
    Number of client care ratings returned = 37
    Number of client care ratings not available = 100

5. Nutrition and Hydration

Mean = 2.45
Range 1 to 3
Number of client care ratings returned = 51
Number of client care ratings not available = 81

6. Medication Monitoring

Mean = 2.61
Range 1 to 3
Number of client care ratings returned = 60
Number of client care ratings not available = 77

7. Symptom Status and Control

Mean = 2.51
Range = 1 to 3
Number of client care ratings returned = 55
Number of client care ratings not available = 82

8. Skin Integrity and Maintenance

Mean = 2.70
Range = 1 to 3
Number of client care ratings returned = 53
Number of client care ratings not available = 84

9. CNS Function

Mean = 2.52
Range 1 to 3
Number of client care ratings returned = 56
Number of client care ratings not available = 81

10. Bowel and Bladder Function

Mean = 2.53
Range 1 to 3
Number of client care ratings returned = 55
Number of client care ratings not available = 82

11. VS Monitoring

Mean = 2.73
Range = 1 to 3
Number of client care ratings returned = 59
Number of client care ratings not available = 78

12. Overall Physician Rating of Services Provided

Mean = 2.68
Range = 1 to 3
Number of client care ratings returned = 59
Number of client care ratings not available = 78

* Note that physician satisfaction ratings are sent only after a client has expired. The number of client care ratings not available thus reflect ratings sent out but not returned and clients who are continuing to receive pilot project services.