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An exploration of the non-medical home care needs of persons with acquired immune deficiency syndrome (AIDS)

Pola Lopez Bouton

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AN EXPLORATION OF THE NON-MEDICAL HOME CARE NEEDS OF PERSONS WITH ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)

A Project
Presented to the Faculty of California State University, San Bernardino

In Partial Fulfillment of the Requirements for the Degree Master of Social Work

by
Pola Lopez, Bouton

June 1993
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PERSONS WITH ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)

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Pola Lopez Bouton

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5/27/93
Abstract

This qualitative study sought to identify the non-medical home care needs of persons with AIDS involved with the In-Home Supportive Services Program (IHSS) in the Rancho Cucamonga service area of the San Bernardino County Department of Aging and Adult Services (N=6). The study was further directed to the IHSS response to those needs.

The research concluded that the non-medical home care needs of persons with AIDS replicate, for the most part, those of other chronically and terminally ill individuals and are adequately being met by IHSS within the limitations of the program. Some differences that did emerge in the research is the frailty and relatively short-term IHSS involvement of the AIDS client and the increased need for infection safety precautions. In addition, some difference in the service delivery of IHSS to persons with AIDS was noted.
Acknowledgments

This researcher would like to acknowledge the assistance of Barton Bonner, Supervising Social Worker, Department of Aging and Adult Services. Barton Bonner took time from his busy caseload to help access and gain the participation of the research sample. In addition, he was always patiently available to answer questions and clarify issues.

The contribution of Farnum L. Bouton for his assistance in proofreading and otherwise is also acknowledged.
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Introduction

The literature describes the progression of the illness of persons with AIDS (PWAs) on a continuum to include individuals who are "apparently well, acutely ill, chronically ill, and terminally ill" (Bartlett and Finkbeiner, 1991; Martin, 1988, p. 468). Although most AIDS patients will require acute care and/or hospitalization at some point in their illness, AIDS is "essentially a chronic illness that requires ongoing patient care and monitoring to reduce intensive hospital stays and critical care needs" (Rowe and Ryan, 1987, p. 8). The progression of the symptoms and impairments experienced by PWAs ultimately requires the need for long term care, which, traditionally, for the chronically and severely ill individual, has included the alternative of the skilled nursing facility (Crystal, Merzel and Kurland, 1990).

The skilled nursing facility (SNF), however, does not appear to be a viable option for most PWAs due to a variety of reasons. One of these is the fear of contagion by SNF staff, patients and families. Another is the fact that most PWAs ultimately become MediCal dependent, while SNFs prefer private pay patients (Crystal et al., 1990; Droeste, 1987; Benjamin, 1988). Since SNFs usually operate near full capacity with excessive demand, they can select the types of patients and payers they want, which usually results in the exclusion of PWAs (Crystal et al, 1990).
PWAs are also reluctant to enter SNFs for many reasons, including those shared with other chronically ill. A primary reason is concern regarding the quality of care, while another is the concept of being warehoused for death with an old population (Crystal et al., 1990).

According to Faye Culpepper-Carson, Inland AIDS Project, since SNFs are likely to exclude the PWAs and San Bernardino County does not have the alternatives of hospice or group homes, which are available in the surrounding counties of Los Angeles and Orange, ultimately, the only two alternatives of care available to PWAs in San Bernardino County are acute care hospitals or home care. In addition, as is true for the elderly and other chronically ill individuals, recent planning for AIDS care has been directed to a service system that allows PWAS "to stay out of the hospital, remain at home and function independently in the community for as long as possible" (Benjamin, 1988, p. 435).

Problem Statement

The literature indicates that most PWAs will eventually become dependent on public assistance and/or MediCal (Benjamin, 1988; Crystal and Jackson, 1989; Crystal et al., 1990; Jacobson, Lindsey and Pascal, 1989). Accordingly, the majority of PWAs will eventually need or become eligible for In-Home Supportive Services (IHSS). As discussed herein, IHSS is the publicly funded, non-medical home care program designed to help the low income, functionally impaired individual,
remain safely at home. The care allotted under IHSS may range from a few hours a week for light housekeeping, laundry and shopping, to extensive personal care, including such chores as bathing, dressing, bowel and bladder care, feeding assistance, paramedical services and protective supervision, up to a maximum total of 283 hours per month.

In San Bernardino County, the operation of the IHSS program has recently changed from the Department of Public Social Services (DPSS) to the newly formed Department of Aging and Adult Services (DAAS). After a referral or application for service is received by DAAS, the perspective IHSS recipient is assigned a social worker. The social worker makes the initial needs assessment and allot hours of IHSS service determined by the assessment. Periodic evaluations are done on a yearly basis or as needed. Each social worker works with a homemaker supervisor who assists the client in locating a homemaker and fields a majority of the client-homemaker problems.

Martin (1988, p. 465) states that the traditional in-home care patient has one or two physical and social complications which only require intervention on an intermittent basis, while PWAs have "three or four opportunistic infections, a complicated social history and extensive psychological needs." This necessitates adjustments to "care plans more frequently that is the case with most other long-term-care patients" (Crystal, et al., 1990).
Crystal et al. (1990) also state that because of the complications of the illness, the need for high-tech home care services is more frequent. AIDS clients on IHSS may also need more assistance in the early stages of the illness to sort through eligibility for various resources, as well as in the terminal stages, when their emotional needs may also be greater (Martin, 1988).

The provider question, always difficult, may become even more so with the PWAs, with fear of contagion and other issues entering the picture. Faye Culpepper-Carson states that, while family members usually come forth to care for the AIDS gay client, this is not true of the individual whose infection source is IV drug use as this individual has most likely "burnt up" his family and resources from past behavior.

According to McDonell, Abell and Miller (1991), attribution of responsibility for acquiring AIDS, fear of stigma and transmission, as well as historical family patterns of interaction and response to crises all impact on the family's willingness to act as care provider and on the quality of care provided. Pearlin (1988) adds that when family members or friends act as caregivers, the prior relationship may change or be redefined which can result in conflict and/or resentment. When speaking about families of PWAs, many in the literature have expanded the definition to include lovers, friends and significant
others as well as the nuclear biological family (McDonnell et al., 1991; Cates, Graham, Boeling and Tielker, 1990).

Literature Review

A review of the literature reveals that most of the AIDS literature deals with disease epidemiology and medical care and costs rather than service delivery (Jacobson et al., 1989). The literature on home care is usually limited to a discussion of home health care rather than non-medical home care (Blanchet, 1988; Droeste, 1987; Jacobson et al., 1989; Smits, Mansfield and Singh, 1990), with the exception of pilot AIDS programs (Crystal et al., 1990; Little, Long and Kehoe, 1990). Yet, it is non-medical home care or homemaker attendant care which meets the individual's practical needs of everyday living that allows the person with AIDS to remain at home and "constitutes the largest number of hours of service provided" (Katoff, 1992, p. 237; Little, et al., 1990).

This research sought to explore this relatively new service field, which is projected to grow as the AIDS population increases, to answer the question: What are the service needs of the IHSS recipient with AIDS and how are they being met? It was hoped that this post-positivist qualitative field study would benefit the direct practitioner as well as the community worker and administrator as it identified possible service gaps and unmet needs as well as the
adaptability of the IHSS program in meeting the needs of PWAs.

Research Design and Methods

The purpose of this exploratory study was to examine the success of the IHSS program in meeting the needs of the AIDS recipient. It attempted to identify and explore problem areas and unmet needs, including provider and family issues as they related to the service delivery of IHSS to PWAs in an attempt to discover:

What are the service needs of the IHSS recipient with AIDS and how are they being met?

Is the current IHSS method of service delivery appropriate to persons with AIDS?

What provider issues confront the IHSS recipient with AIDS?

What role does the family play in the service delivery of IHSS to persons with AIDS?

This exploratory study employed a post-positivist method of inquiry, using the qualitative methods of participant observation and individual field interviews, augmented by analysis of IHSS service files, including IHSS assessment and enrollment forms (Appendix A).

Scope

This research was limited to the Rancho Cucamonga service area of the San Bernadino County Department of
of Aging and Adult Services (formerly Department of Public Social Services), which currently encompasses the cities of Rialto, Fontana, Bloomington, Lytle Creek, Rancho Cucamonga, Montclair, Upland, Ontario and Chino. The IHSS recipients with AIDS usually averages 20 open cases in this service area. The population fluctuates due to deaths, changes of residence and other reasons. Because of this relatively small population, the research sought to include all open IHSS cases involving PWAs, which, at the start of data collection, numbered 17. Three other cases were opened during data collection and these were also invited to participate in the research. The research also attempted to include caregivers, whether family members or unrelated IHSS providers. The data collection period was limited to a ten week period and was done by one researcher.

There is currently one Supervising Social Worker in the Rancho Cucamonga Service area who is the caseworker for all IHSS cases involving PWAs in the service area. This Supervising Social Worker was utilized to gain the participation of the target population in this research. At the end of the research, this Social Worker was also interviewed (See Appendix B for interview content) to answer questions raised in the research and for his input and expertise with the research content.
Data Collection

Initially, an invitation letter (Appendix C) and consent (Appendix D) were sent to all 17 IHSS recipients with AIDS, under the signature of the Social Worker, describing the research and inviting participation. When no responses were received to this mailing after a two to three week period, the Social Worker began to remind clients about the research and to question their willingness to participate as they contacted him for other matters. Through his efforts, the participation of a mother and her 18 month old child was obtained as well as a new recipient who had been placed on service at or about the time of the initial mailing and, because his case was being processed for service, had been overlooked in the initial invitation mailing.

When no other responses were received, the researcher sent out another letter requesting participation (Appendix E), again under the signature of the Social Worker, but this time offering a movie pass (Appendix F) as an inducement to participation in this research. This researcher received four responses to this second letter, all agreeing to participate. Of these four, one was hospitalized and subsequently died before a scheduled appointment for an interview took place.

In addition, the Social Worker also heard from two other recipients declining participation. One reported he was in remission and no longer needed IHSS, and the other declined
to participate because he was mourning the death of an uncle from AIDS and did not feel he could discuss the illness at the time. Two new cases were opened at this time and invitation letters were mailed to these recipients. Another of the original 17 PWAs initially contacted for this research also died during this period.

In summary, of the total target population of 20, 2 died during the data collection period, 2 responded but declined to participate and 6 agreed to participate. Although all IHSS recipients with AIDS participating in the research were willing to have their homemakers interviewed, only two homemakers agreed to participate. One of these was a sister/aunt to the mother/child dyad. No other family members participated. The sister/aunt homemaker chose to be interviewed by telephone. All other interviews were conducted in the home of the participant, by appointment.

**Instruments**

The researcher had anticipated that the questions devised for the interview of the IHSS recipient with AIDS (Appendix G, Part 2) would act as guidelines and that, in the actual interview sessions, open ended responses would elicit other questions and information. This, in fact, did not frequently happen and the home interview consisted, for the most part, of the questions on Appendix G, Part 2, and the Assessment of Client Functioning, Part 1. This was due, in part, to the frailty of the population and the
efforts of the interviewer to be as unobtrusive as possible. The interviews of the IHSS recipients were approximately one hour in duration.

Questions regarding psychological well-being and quality of life, suggested by Rinke (1987), were initially proposed to be included in the interview of the PWAs but were eliminated prior to the interviews as not being pertinent to the research, with the exception of question 23, (Appendix G, Part 2) regarding sufficiency of privacy. For this same reason, questions regarding contagion source and lifestyle were also avoided but this information emerged voluntarily in the interview. Other questions were also deleted after the first participant interview as being repetitious, irrelevant or not applicable. Interview time of the collateral participants was much shorter and the interviews consisted of the questions indicated in Appendix H and I. After the first interviews with the family member and the IHSS provider, these appendices were also adjusted, with some deletions and additional questions regarding agency interaction included. Unfortunately, no other family members or providers participated and, thus, the adjusted instruments were not utilized.

Results

The data obtained from participant observation and interviews was categorized and analyzed using the qualitative
methods of open and selective coding. Information gained from collateral contacts and case service records was similarly categorized and analyzed to further verify and clarify participant report and to identify IHSS service needs and agency response thereto. Demographic information from the State of California and the San Bernardino County Public Health Department was also utilized in the analysis of the data to give some perspective of the relationship of the research population to the general IHSS and AIDS population in the service area of San Bernardino County.

Demographic Characteristics

An initial step in the analysis was to establish the demographic characteristics of the research population. As Table 1 indicates, the greatest number of participants in the research were white males, with probable AIDS infection source being male to male sex. All lived in a shared living situation, whether with an IHSS live-in provider or otherwise. This included the mother and minor child, who lived with each other. Of the three who lived with their provider, two were categorized as having a live-in provider, while the third was designated as a shared living arrangement. All but one of the participants stated that the present living situation was better than the last one previous. For example, one related that he had been homeless prior to the present living situation and two related they had been living with a parent in a crowded situation.
### TABLE 1.

**Demographic Characteristics**

(N = 6)

<table>
<thead>
<tr>
<th>Age</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>- 2 years</td>
<td>1</td>
</tr>
<tr>
<td>20-29 years</td>
<td>2</td>
</tr>
<tr>
<td>30-39 years</td>
<td>1</td>
</tr>
<tr>
<td>40-49 years</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>5</td>
</tr>
<tr>
<td>Female</td>
<td>1</td>
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</table>

<table>
<thead>
<tr>
<th>Referral Source</th>
<th>N</th>
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<tbody>
<tr>
<td>Self</td>
<td>3</td>
</tr>
<tr>
<td>Family</td>
<td>2</td>
</tr>
<tr>
<td>AIDS Project</td>
<td>1</td>
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<table>
<thead>
<tr>
<th>Income</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>SSI</td>
<td>3</td>
</tr>
<tr>
<td>SSI/SSA</td>
<td>2</td>
</tr>
<tr>
<td>SSA-Share of Cost</td>
<td>1</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Relationship to Provider</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family member</td>
<td>3</td>
</tr>
<tr>
<td>Non-related friend</td>
<td>2</td>
</tr>
<tr>
<td>No previous relationship</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Without IHSS</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recipient at Risk</td>
<td>5</td>
</tr>
<tr>
<td>Recipient will require</td>
<td></td>
</tr>
<tr>
<td>non-medical out of home placement</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>White (Not of Hispanic Origin)</td>
<td>3</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
</tr>
<tr>
<td>Black</td>
<td>2</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Living Arrangement</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live-in provider</td>
<td>2</td>
</tr>
<tr>
<td>Shared with provider</td>
<td>1</td>
</tr>
<tr>
<td>Shared with non-provider</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Length of IHSS Involvement</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 2 months</td>
<td>1</td>
</tr>
<tr>
<td>3 - 7 months</td>
<td>3</td>
</tr>
<tr>
<td>23 months</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Probable Infection Source</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male/Male</td>
<td>3</td>
</tr>
<tr>
<td>Male/Male/IDU</td>
<td>1</td>
</tr>
<tr>
<td>Heterosexual/Male IDU</td>
<td>1</td>
</tr>
<tr>
<td>Perinatal Transmission</td>
<td>1</td>
</tr>
</tbody>
</table>
Five of the 6 recipients received Social Security Supplemental Income (SSI) or a combination SSI and Social Security Administration Disability (SSA) which made them status eligible for IHSS with no share of cost. Only one of the participants received enough income from SSA to make him income eligible for IHSS with a share of cost of $96.00. Ironically, this was the individual who reported the least stable lifestyle, disclosing that he had been a constant runaway as a youth, as well as a male prostitute and injection drug user.

Most of the referrals or requests for service were initiated by the recipient or her/his family. The length of time on IHSS service ranged from two months to 23 months. When questioned on average length of IHSS service involvement for AIDS clients, the Social Worker indicated that it varied but noted that he is now finding that length of IHSS involvement has increased from less than one year to two years or more for a growing number of PWAs. When questioned further if he could attribute this to the fact that this population was asking for help sooner, the Social Worker responded negatively, and added that many call IHSS only after being referred by Hospice. Instead, the Social Worker hypothesized that improved medications are extending the life of this population.

Four of the 6 recipients with AIDS were very frail, with two reporting T-Cell counts of less than 10, with the normal
T-Cell count being 800 to 1400. Two usually were dependent on a walking aid. All reported varying severity of multiple symptoms or opportunistic illnesses. All reported that their physical condition varied to the extent that sometimes they were unable to get out of bed. The Social Worker rated 5 of the recipients as at-risk without IHSS and 1 as requiring non-medical out-of-home care without IHSS.

Although three of the recipients indicated that they had been hospitalized at least one time since being on IHSS, only one indicated that receipt of IHSS was a factor in being released home. None of the recipients had ever been in a SNF nor felt themselves in immediate danger of being placed in a SNF.

Five of the 6 recipients reported mental deterioration, demonstrated by forgetfulness and memory loss. The mother of the 18 month old recipient related that it is difficult to determine if there has been mental impairment because the toddler has no language and developmental milestones are still open to interpretation.

All of the residences were adequately to extremely clean as was the personal appearance and grooming of the participants.

**Service Needs**

As noted, participant report as well as IHSS assessment forms were utilized to ascertain the service needs of this population. Table 2 describes the allotment of IHSS hours for various service needs. To be further noted is the fact
that there are certain time guidelines to be followed to determine hourly needs. For example, the maximum time allotted for domestic service under IHSS is 4.11 hours per month. If there are others in the home, this amount is normally prorated by the number sharing the home. This proration is also applicable for related services, which includes meal preparation and cleanup and shopping. A live-in provider arrangement is exempt from this proration.

**TABLE 2**

IHSS Service Hours  
(N=6)

<table>
<thead>
<tr>
<th>Service</th>
<th>N</th>
<th>IHSS Monthly Hours</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domestic Service</td>
<td>6</td>
<td>14.55</td>
<td>3%</td>
</tr>
<tr>
<td>Related Service</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meal Preparation and Cleanup and Shopping</td>
<td>6</td>
<td>153.31</td>
<td>33%</td>
</tr>
<tr>
<td>Laundry</td>
<td>6</td>
<td>15.69</td>
<td>3%</td>
</tr>
<tr>
<td>Total Related Service</td>
<td></td>
<td>169.00</td>
<td>39%</td>
</tr>
<tr>
<td>Personal Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowel and Bladder</td>
<td>5</td>
<td>61.23</td>
<td>13%</td>
</tr>
<tr>
<td>Bathing</td>
<td>5</td>
<td>44.12</td>
<td>9%</td>
</tr>
<tr>
<td>Feeding</td>
<td>2</td>
<td>30.31</td>
<td>6%</td>
</tr>
<tr>
<td>Dressing</td>
<td>4</td>
<td>22.13</td>
<td>5%</td>
</tr>
<tr>
<td>Ambulation</td>
<td>1</td>
<td>12.12</td>
<td>3%</td>
</tr>
<tr>
<td>In and out of bed</td>
<td>2</td>
<td>7.14</td>
<td>2%</td>
</tr>
<tr>
<td>Skin Rubs</td>
<td>1</td>
<td>7.14</td>
<td>2%</td>
</tr>
<tr>
<td>Respiration</td>
<td>1</td>
<td>1.08</td>
<td>-1%</td>
</tr>
<tr>
<td>Total Personal Care</td>
<td></td>
<td>185.27</td>
<td>39%</td>
</tr>
<tr>
<td>Paramedical Service</td>
<td>1</td>
<td>28.15</td>
<td>6%</td>
</tr>
<tr>
<td>Medical Transportation</td>
<td>6</td>
<td>73.62</td>
<td>16%</td>
</tr>
<tr>
<td><strong>TOTAL MONTHLY IHSS HOURS</strong></td>
<td></td>
<td>470.59</td>
<td>100%</td>
</tr>
</tbody>
</table>
Domestic service hours were prorated for 4 of the population of 6. Related service hours were prorated in 4 cases as well. None of the other services were prorated or adjusted and the hours assessed as individual needs were the hours authorized to be purchased and provided by IHSS.

Personal care comprised the largest number of hours, with bowel and bladder being the highest percentage of these hours, followed by bathing help. Meal preparation and cleanup and shopping comprised the next largest service need. This seems to indicate that IHSS is required by PWAs for the very basic needs and activities of daily living.

All 6 participants indicated that they had no unmet service needs. Yet 5 indicated that they did not feel that the provider was allotted enough service hours for the care they were providing, especially in lieu of the fact that sometimes they required and received more care due to their up and down condition. When the Social Worker was questioned on this point, he indicated that it is standard IHSS practice to assess for down time and average out the hours. In addition, if the condition changes significantly from the assessment, clients are advised to call and do so. Neither of the two homemakers interviewed indicated that they felt that they consistently did more than allotted. One stated that because the condition fluctuates, on occasion she might do more than allotted but it evens out because at other times the recipient is able to do more for herself.
Although the response time to the request for service varied from 3 working days to 12 working days or more, all of the recipients reported that they rated the response to their request for service as very prompt. When questioned if the response time for these clients is faster than other client referrals, the Social Worker indicated that he does try to respond more quickly to referrals involving PWAs because he recognizes that this population is very fragile.

Four of the recipients had had increases to their initial IHSS assessed hours. Of these, one had one increase, two had two increases and one had three increases.

All of the recipients rated the treatment they had received from the Social Worker and the department as "excellent" to "good". Only one of the recipients had complaints about his homemaker whom he rated as a bit irresponsible but indicated that he was willing to put up with this because he provided him with companionship and support which he rated higher than job performance. It is to be noted that this was the recipient who had no previous relationship with his provider and was only involved through IHSS.

When questioned whether the standard of care and cleanliness was up to their standards, all but one indicated that it was at their standard or better.

One recipient indicated that she felt that the IHSS department should monitor the situation more closely and have
more contact, as did one homemaker, not involved with this client. The two recipients on service the longest felt that follow up was adequate and felt the IHSS Social Worker was adequately involved.

Safety precautions against infection may be more of an issue with the IHSS recipient with AIDS than otherwise. When questioned regarding precautions taken, most responded that cleanliness of person and environment was stressed. This was visually verified. In addition, the provider tries to stay away if s/he is ill and ensures that visitors are not allowed if they are ill. The homemaker for the mother/child dyad reported that she will take the child home with her when the mother is manifesting symptoms that might be an infection source for the child.

**Provider Issue**

Of the problems involved with the service delivery to this population, the Social Worker indicated that the most difficult was finding providers who were willing to work with the AIDS client. The service records in the research population indicated that all had their own provider at the time of the initial assessment. Four of these have had the same homemaker since being on service in San Bernardino County. Of the remaining two, 1 has had four homemakers during his 23 month IHSS involvement and 1 has had two homemakers during 7 months of IHSS involvement. In addition, the latter individual indicated that two other persons had
committed to be his homemaker but never showed up or became involved with the program. Although neither of the recipients gave their AIDS diagnosis as a reason why their homemaker terminated or declined to become involved, there was evidence in the service file that this was the case in at least one of the situations.

**Family Involvement**

As noted, family members acted as the IHSS provider in 3 of the cases in our research sample. In another of the cases, the father provided medical transportation. In another case, a sister had initially tried to help care for the client but was acting as IHSS provider to an elderly mother and could not continue to provide care. In summary, in 50% of our sample, a family member acted as the primary provider and in another case the family member supplemented IHSS by providing medical transportation. When questioned regarding the impact on the family relationship, all recipients indicated that the relationship was better and closer than it had been. This sentiment was also voiced by the one family member participating in the research, and was also the judgment in the cases where a long term friend acted as IHSS provider.

**Discussion**

The research findings appear to point to the conclusion that the non-medical home care needs of the IHSS recipient
with AIDS, encompassing assistance with every activity of
daily living, replicate those of other chronically and
terminally ill individuals on IHSS, and, further, that those
needs are being met within the limitations of that program.
One possible difference that does emerge that may be noted
here is, due to the high susceptibility of this population
to infection, there may be a stronger need for cleanliness
of person and environment. Traditionally, the allotment
for domestic service within the IHSS program has been low
since the purpose of the program is not so much housekeeping
help but provision of service to meet the very basic needs
of daily living to prevent the recipient from being placed
at-risk. For the AIDS client, cleanliness may become an
at-risk issue and, accordingly, the allotment of IHSS hours
for domestic service for PWAs may warrant reexamination.

Another conceivable difference between PWAs and other
chronically ill on IHSS may be the relatively short term
IHSS involvement of the PWAs, even though the Social Worker
indicated that this may be changing. A follow up on the
research sample six months after data collection indicated
that 2 of the research sample of 6 had died, both of whom
were each involved with IHSS for only an 8 month period.
Of the targeted population of 20, 7 (35%) had died during
the same six month period. This emphasizes the frailty of
this population and that the need for expediency of service
may be greater than for other IHSS clients.
However, the most significant difference appears to be in the manner in which the AIDS client on IHSS is perceived. This is poignantly demonstrated by the fact that all AIDS cases are essentially segregated and assigned to one worker. When questioned about this practice, the Social Worker indicated that he had initially taken all AIDS cases in the service area because no one else wanted to do so and, since he knew these clients were being rejected by family, agencies and others, he wanted to prevent a further rejection. In addition, the Social Worker indicated that, as he became more involved, he gained expertise in this field and became more readily able to recognize service needs.

From client report, it does not appear that the PWAs have been detrimentally impacted by this segregation. In fact, the opposite may be true. More than one of the participants expressed their appreciation for the accepting manner in which they were treated, and all expressed satisfaction or praise for the IHSS response to their needs. Yet one has misgivings about a practice that arbitrarily segregates a population from the mainstream. Separate but equal, or even separate but superior, would not appear to have a place in current social work practice. In addition, current research is fairly conclusive that casual contact, such as that between social worker/client is not a source of infection. This apparent fear among the staff involved with IHSS service delivery would appear to dictate the need for
education and training among these workers.

Although this study did not explore if the psychological needs of the AIDS population on IHSS are greater or different than others on IHSS, it did emerge that there are counseling needs, some of which may be shared with other terminally ill on the program. These include issues of denial and death and dying. Others may be unique to the AIDS client. For example, the mother in the study was not only dealing with death and dying issues herself, but was also having to cope with these in regards to her child. In addition, she was faced with the issue of who would die first and the anguish of transmission. Only one of the subjects in the sample was actively involved with a support group. The most cited reason for not being in counseling or a support group was access to service, due to lack of transportation or a weakened physical state. The research supports the need for in-home counseling that would probably have to be served by a community resource as it appears to be out of the realm of the IHSS program.

Provider Issue

The data was too limited to make an accurate assessment of provider issues or to determine if the provider issues facing PWAs are different from the general IHSS population. The following points regarding providers did emerge from the research and are noted here. The providers involved in the research had educated themselves by reading the literature
on AIDS and felt adequately prepared to care for the AIDS client. This might not be universally true and education might be indicated for providers of this population. The recipient who expressed the most dissatisfaction with his homemaker was the only one who had no prior relationship with his provider. Dissatisfaction with the rate of pay and the length of time to receive pay checks was also expressed but these may be common complaints among IHSS providers and, in all fairness, were expressed by recipients in support of their providers.

Limitations

The small sample size does appear to limit the generalization of the research findings. After all, even though the sample is 30% of the current AIDS population on IHSS in the service area, current demographic information from the San Bernardino County Department of Public Health would indicate that this is less than 5% of the AIDS population in the Rancho Cucamonga service area. (March 1993 statistical information from the State of California indicates that there are currently 3,104 open IHSS cases in the Rancho Cucamonga service area, making the average of 20 cases involving PWAs less than 1% (.006) of the total IHSS cases in the service area.) On the other hand, it is felt that the research sample is fairly representative of the general AIDS population in the area and that the symptoms and needs described are also indicative of the general IHSS
needs of PWAs, although, of course, this exploratory study cannot be considered conclusive on this subject.

Another possible limitation to the generalization of this research might be the fact that only one social worker was involved in the service delivery. One could argue that the research emerges as merely an assessment of that social worker's performance. On the other hand, the assessment methods and allotment of IHSS service hours are standardized and fairly rigid and should, in theory, not differ greatly among workers, even allowing for practice methodology differences. In addition, the provider also has an effect on service delivery and the providers were varied in the research sample. Despite the qualifications regarding the generalization of the research and the concerns regarding service delivery, it does appear that the safety of PWAs is being provided and out-of-home placement avoided, because of the implementation of IHSS. Furthermore, the IHSS program appears to be as receptive to the needs of PWAs in the Rancho Cucamonga service area as other recipients of the program.
# APPENDIX A

## IN-HOME SUPPORTIVE SERVICES ASSESSMENT

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Department of Social Services

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25
## APPENDIX A

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**SCC 213 (1) 13115 PART**

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## APPENDIX A

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</tr>
</tbody>
</table>
APPENDIX A

SOC 293 CODE SHEET

AID CODE (Field A-3)
10 - Aged, Status Eligible
18 - Aged, Income Eligible
20 - Blind, Status Eligible
28 - Blind, Income Eligible
60 - Disabled, Status Eligible
68 - Disabled, Income Eligible

ETHNIC CODE (Field F-3)
1 - White (Not of Hispanic Origin)
2 - Hispanic
3 - Black (Not of Hispanic Origin)
4 - Asian or Pacific Islander
5 - American Indian or Alaskan Native
7 - Filipino

SPouse/PARENT CODE (Field C-1)
00 - None - Recipient lives alone
11 - Spouse - Able and Available
12 - Spouse - Able/Partially Available
13 - Spouse - Able/Not Available
14 - Spouse - IHSS Recipient
21 - Parent - Provides All Services
22 - Parent - Provides Some Services
23 - Parent - Provides No Services
24 - Parent - IHSS Recipient

STATUS CODE (Field Fl)
R - Record - Pending Application
I - Interim eligibility - PE
E - Eligible - Regular Approval or Confirm PE
L - Leave - Temporary Suspension
D - Discard/Deny
X - Delete - Erroneous Record

LANGUAGE CODE (Field F-4)
1 - Spanish
2 - Chinese
3 - Japanese
4 - Korean
5 - Filipino (Tagalog)
6 - Other Non-English
7 - English
8 - Vietnamese
*Notice of Action will be issued in Spanish

RESIDENCE - TYPE OF DWELLING CODE (Field G-4)
01 - House
02 - Apartment
03 - Mobile Home
04 - Hotel
05 - Other

LIVING ARRANGEMENT CODE (Field G-5)
01 - Independent
02 - Shared
03 - Live-in-Provider
04 - Tenant/Landlord
05 - Board and Room

NOTE: Number in Household (G-2) and Number Recipients (C-3) are two digit fields; therefore, leading 0's are required.

FUNCTIONAL LIMITATIONS CODES (Field H-1)
(Use Only One)
A. Physical Functioning
1 = With Ease
2 = Some Difficulty
3 = Very Difficult
4 = With Human Support
5 = With Appliance
6 = Not At All
B. Mental/Emotional Functioning
1 = No Problem
2 = Moderate or Intermediate Problem
3 = Severe Problem

NOTE: Share of Cost/Countable Income Fields are used only in Income Eligible (IE) cases. At least Fields I(1), I(3), and J(4) (Code) are required for all IE's in order to issue a correct Notice of Action. To obtain an automated Countable Income Computation, Fields I(1) and (2), and J(1); and J(3); K(2); and L(2) as applicable must be completed.

LINK CODE (Field J-1) (Use 1 or 2)
01 - IHSS Individual
02 - IHSS Individual/Linked Spouse
03 - IHSS Individual/Non-Linked Spouse
04 - IHSS Individual/Non-Linked Parent
05 - IHSS Individual/Non-Linked Parents

WITHOUT IHSS CODES (Field H-2)
2 - Recipient at Risk
3 - Will Require Non-Medical Out Of Home Care
4 - Will Require Medical Out Of Home Care
5 - Will Become Unemployed

NEED PROVIDER (Field H-3)
00 - Recipient Has Own Resources
11 - Recipient Needs Help Finding Provider

SOURCE CODE (Fields I(2), J(3), K(2), L(2))
01 - RSDI - Recipient
02 - VA - Recipient
06 - Railroad Retirement - Recipient
07 - Other Pension - Recipient
08 - Spouse/Parent - Unearned
09 - Spouse/Parent - Earned
### APPENDIX A

**SOC 293 CODE SHEET**

**PAGE TWO**

**BENEFIT CODE (Field J-4)**

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<td>3</td>
<td>Individual Disabled Minor - Own Home</td>
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<td>4</td>
<td>Individual Aged Or Disabled - Household Of Another</td>
</tr>
<tr>
<td>5</td>
<td>Individual Blind - Household Of Another</td>
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<td>6</td>
<td>Individual Disabled Minor - Household Of Another</td>
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<td>7</td>
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**REFERRAL CODE (Field P-2)**

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<td>Adult Day Health Care Center</td>
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<td>Early Hospital Discharge (Diagnostically Related Groups)</td>
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<td>Preadmission Screening/Gatekeeper</td>
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<td>Other</td>
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APPENDIX B

Interview of Social Worker

1. Does your response time to an IHSS AIDS referral differ from other IHSS referrals?
2. Do you assess your AIDS cases any differently than your non-AIDS clients?
3. How often do you reassess?
4. Do these clients call frequently?
5. Is most of the contact you have with these clients initiated by you or the client?
6. Why do you handle all the AIDS cases?
7. Is this the general rule throughout the county?
8. Do you feel the provider problems are any different from your regular IHSS clients?
9. Do you feel the needs are different?
10. Do you remember how long you have had AIDS clients?
11. Are you able to give an approximate average length of IHSS involvement for the AIDS client?
12. What is the average AIDS caseload?
13. Other than_________, none of the people I interviewed had any contact with the IHSS supervisor. Do you handle both IHSS and provider issues? If so, why?
14. It seems that only one of the persons I interviewed had a homemaker who was essentially a stranger. Do you find that this is the rule for most AIDS clients
APPENDIX B

on IHSS?

15. I know time restraints limit your involvement with clients. Do you think the time you spend is adequate and all things being perfect regarding time restraints you would not spend more time?

16. The AIDS client tells me that his condition is up and down. Do you take this into consideration in allotting IHSS hours?

17. When asked regarding support group involvement, distance impacts on involvement. Do you see a need for counseling?

18. Do you see unserved needs?

19. How will recent 12% cuts in IHSS hours affect the AIDS client?

20. Do you have anything to add to the research?
APPENDIX C

Invitation Letter

This letter is written at the request of Pola Lopez Bouton, a social worker in the Adult Protective Services unit of this agency. Under the auspices of California State University, San Bernardino, Ms. Bouton is conducting a research into the service delivery of In-Home Supportive Services (IHSS) to persons with AIDS, with emphasis on caregiver or provider issues.

Ms. Bouton has asked me to send this letter to all my IHSS clients with AIDS to ascertain if they would be willing to participate in this research. I am informed by Ms. Bouton that your involvement would entail a personal interview by her of approximately one hour. Pola would also like to interview any family members involved in your homemaker services and your IHSS homemaker. In addition, she would like to examine your IHSS file which contains such information as hours allotted, service needs and homemaker information.

If you would be willing to participate in this research, please return the attached letter of consent to me in the enclosed self-addressed stamped envelope. I will deliver your consent to Pola Bouton, who will then contact you by telephone to set up an appointment at your convenience. Pola Bouton will not be provided with any information about you for this research unless you return this consent. If you would like to discuss participation in this research with Pola Bouton, you may contact her at the office at 945-3831.

Your involvement in this research will be kept strictly confidential and private and is completely voluntary.

Sincerely,

BART BONNER
Supervising Social Worker
APPENDIX D

CONSENT

I consent to participate in the research into the service delivery of In-Home Supportive Services (IHSS) to persons with AIDS being conducted by Pola Lopez Bouton, under the auspices of California State University, San Bernardino.

I understand that the purpose of this research is to examine the success of the IHSS program in meeting the needs of the AIDS recipient, to identify provider and family issues and to explore problem areas and unmet needs.

I understand that my involvement will entail a personal interview with Pola Bouton of me and any family members involved in my homemaker services and my IHSS homemaker.

I also hereby authorize the San Bernardino County Department of Public Social Services to release any information regarding my IHSS to Pola Lopez Bouton and hereby grant her permission to examine my IHSS service file for purposes of this research.

I understand that my participation is voluntary and that all information is confidential and that my identity will not be revealed. I am free to withdraw consent and to discontinue participation in the project at any time. Any questions that I have about the project will be answered by the researcher, Pola Lopez Bouton, or by the project supervisor, Marjorie Hunt, Ph.D., California State University, San Bernardino, at (714) 880-5496.

California State University, San Bernardino, and the researcher named below have responsibility for insuring that participants in research projects conducted under university auspices are safeguarded from injury or harm resulting from such participation. If any concerns in this regard should arise, I may contact the researcher indicated below, or Dr. Marjorie Hunt, at 880-5496.

On the basis of the above statements, I agree to participate in this project.

Participant's signature Date

Researcher: Pola Lopez Bouton
P. O. Box 1088
Rancho Cucamonga, California 91730
Work: 945-3831
APPENDIX E

Invitation Letter

(2)

DEPARTMENT OF PUBLIC SOCIAL SERVICES

COUNTY OF SAN BERNARDINO
SOCIAL SERVICES GROUP

JOHN F. MICHAELSON
Director

It has been several weeks since I wrote to you asking for your participation in a research being conducted by Pola Bouton, under the sponsorship of California State University, San Bernardino. As I informed you, the purpose of the research is to examine the success of the IHSS program in meeting the needs of the AIDS recipient and to explore problem areas and unmet needs, including homemaker issues.

Very few IHSS recipients have responded to that letter and Pola has requested I write another letter urging your participation in this research. As I informed you previously, your participation would entail an interview, in your home, of about one hour. Although Pola would also like to talk to your homemaker and/or family members involved in your homemaker services, Pola would still like to talk to you even if you prefer that your family and/or homemaker do not become involved in this research.

To try to encourage you to participate, Pola is offering a movie pass for two to the General Cinema Montclair to each individual agreeing to participate in this research. As noted before, your involvement in this research will be kept strictly confidential and private and is completely voluntary.

If you would be willing to participate in this research, please return the consent previously mailed to you, or, if you prefer, you may call me at 945-3858 or Pola Bouton at 945-3831.

Sincerely,

BART BONNER
Supervising Social Worker

34
This letter will admit you and one guest to see any feature at General Cinema Montclair 1-3 or General Cinema Montclair 4-8.

Just present this letter to the box office and our cashier will present you with your admission ticket(s). These tickets are good only on the date that they are issued.

Occasional contractual obligations with certain distributors and the presentation of special features may restrict the use of this pass.

If you have any questions please call us at 714-621-9169.

Expires SEP 30 1992

Sincerely,

William Saugez
Manager
APPENDIX G

Part 1

Assessment of Client Functioning

Assessment of physical appearance of client and residence:

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<tr>
<th></th>
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<th>Dirty Inadequate</th>
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<tr>
<td>Yard</td>
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<td></td>
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<tr>
<td>appropriate clothing</td>
<td>1  2 3 4 5</td>
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</tr>
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</table>

Physical manifestations of illness:

Skin:
Mobility:
Robust or frail:
Voice:
Breathing:
Dependency:
Other:

Description of present state of health:

Physical:
Mental:
APPENDIX G

Part 2

Interview of IHSS Recipient

1. Do you think it took a long time from the time you made the request for IHSS until the time you began to receive the services?

2. Did this cause you any hardship?

3. Were you able to care for yourself before you started receiving IHSS?

4. If not, who was caring for you?

5. When was the last time you were hospitalized?

6. How long was your hospitalization? What was the diagnosis of your hospitalization?

7. Was the fact that you were receiving IHSS a key consideration in allowing you to return home from the hospital?

8. How often have you been hospitalized since you have been on IHSS?

9. Have you been placed in a skilled nursing facility? Why? For how long? How did you feel about that?

10. Do you think you could live on your own without IHSS?

11. Do you or your homemaker prepare your meals? How many meals do you eat per day?

12. Do you feel you are eating properly?

13. Are you on a special diet? Does your homemaker follow the diet?
APPENDIX G

Part 2

14. What household chores are you able to do for yourself?
15. What personal care chores are you able to do for yourself?
16. What things are you unable to do for yourself that your homemaker is not doing? Why?
17. Do you need help administering your medication? Does someone give you this help?
18. Does your homemaker provide transportation to the doctor?
19. Does your homemaker provide paramedical services? If so, do you think she is trained to do so?
20. Have you changed residences since your illness? How do you feel about that? Would you change your living situation if you could?
21. Does your homemaker live with you?
22. Do you feel you need 24 hour care?
23. Is the amount of privacy you have sufficient to meet your needs? (Rinke, 1987)
24. What safety measures do you or your homemaker take to prevent infection?
25. How long have you been on IHSS service?
26. How many homemakers have you had?
27. Why did you change homemakers?
28. Do you like your present homemaker? If not, why
APPENDIX G

Part 2

do you continue with this homemaker?

29. Is your homemaker related to you?
30. If so, has this changed your relationship?
31. Is there anything you don't like about your homemaker?
32. Has your homemaker ever yelled at you?
33. Has your homemaker every shoved or slapped you?
34. Has your homemaker every taken anything of yours without permission?
35. Does your homemaker help you handle your money?
36. How long has this homemaker worked for you?
37. Do you think your homemaker receives enough hours from the IHSS program?
38. Does your homemaker perform all the tasks that s/he is paid to do, as far as you know?
39. Is the care you receive up to your standards or have you made adjustments in your expectations?
40. Are you or your family involved in support groups or services?
41. Does your condition and capacity to care for yourself vary?
42. Do you have needs which are not being served?
43. Have your hours been increased or decreased since you have been on service?
44. When you have questions or problems with your
APPENDIX G

Part 2

homemaker service, who do you speak to?

45. Have you had any trouble getting to talk to your social worker or other workers at the Department of Social Services?

46. How would you rate your contact with the homemaker department?

47. How do you feel about the social worker who works with you?

48. Did your social worker do anything that particularly helped you?

49. Did he do anything that particularly upset you or that you did not like?

50. How much contact do you have with your social worker? Is that enough?

51. Do you remember what you discussed in your last conversation with your social worker?

52. Do you talk to the social worker or the homemaker supervisor more frequently?

53. Do you have any positives or negatives about the program you would like to discuss?

54. May I help you in any way?

55. Do you have anything that you would like to include in this research?
APPENDIX H

Interview of Family Member

1. Are you involved in any way with caregiving or the homemaking service?
2. Are you the primary caregiver or is IHSS used as respite?
3. What assistance do you provide?
4. Do other family members help?
5. Has your relationship changed since you became caregiver?
6. Has your living arrangement changed?
7. Do you have trouble keeping up with household chores?
8. Has the social worker helped you in any way?
9. Are you able to reach the social worker when you need to do so?
10. How often do you see a social worker? Is that enough?
11. In what areas could you use help?
12. Has the social worker directed you to other resources?
13. Have they helped?
14. Do you belong to a support group?
15. Does being the paid provider allow you to be the caregiver?
16. What have you had to give up to become the caregiver?
17. Do you feel that he does all that he is able?
18. Have you ever become so stressed with the care
APPENDIX H

that you have yelled at him? Have you ever struck him?

19. Do they contribute their fair share to the household expenses?

20. Do you think he should be placed out-of-home?

21. Have you ever tried to place him out-of-home?

22. If you are not the caregiver, how do you rate his caregiver?

23. Do you feel that you do more than what you are paid to do?

24. What kind of training did you get? Is that enough?

25. What do you do to protect the patient from infection?

26. How would you rate your knowledge about his illness?

27. Do you have any comments you would like to include in this research?
APPENDIX I

Interview of IHSS Provider

1. How long have you been on the job?
2. Have you worked as an IHSS provider before?
3. Have you had any specific training in caring for an AIDS client? Was it enough?
4. Have you worked for other AIDS clients?
5. Would you work for an AIDS client again?
6. Do you feel your work is important?
7. Do you or have you had any problems with the client's behavior?
8. If you live in, how are the sleep-in conditions?
9. What particular jobs are you asked to perform that you do not like? What, if anything, are things you like about the job?
10. How do you rate the pay? Is it fair for what you do?
11. What safety precautions do you take to protect your client from infection? Yourself?
12. Are you able to talk to your homemaker supervisor?
13. Do you find her supportive?
14. Has anyone given you a hard time because you care for an AIDS client?
15. Do you have any fears connected with this?
16. Do you feel close to your client?
17. Is he demanding?
18. Do you do a variety of chores?
APPENDIX I

19. Do you feel that the information you received about your client was complete?
20. Do you feel he needs services that he is not receiving?
21. Do you have enough supplies and/or equipment?
22. Are you treated with respect?
23. Have you ever lost your temper with your client and yelled at him? Shoved him? Been rough with him?
24. How much contact do you have with the homemaker department? Is that enough?
25. Do you have other concerns that we have not discussed?

(Some of the above questions were suggested by a reading of Feldman, Sapienza and Kane, 1990.)
References


California (1992, April). In-Home Supportive Services Recipient summary characteristics listing. Rept. HIHR522F.


