FINDING THE FIT:

A REVIEW OF THREE INTERVENTION MODELS FOR WORKING WITH HIV/AIDS IMPACTED SUBSTANCE USERS WHO ARE HOMELESS

a

Mid-America Institute on Poverty

Research and Policy Report

February, 1999

HEARTLAND ALLIANCE

Providing paths from harm to hope since 1888

Mid-America Institute on Poverty
4411 N. Ravenswood, 2nd Floor
Chicago, IL 60640
773-728-5960x275

ACKNOWLEDGMENTS

Authors

Amy Rynell, *Policy & Advocacy Specialist, Mid-America Institute on Poverty*
Maryann Mason, *Director, Mid-America Institute on Poverty*

Editorial Assistance

Special thanks to the following people from Rafael Center, FirstStep, BEHIV, CSLS and AFC who provided information and assistance throughout the project:

Robert Butler, *Case Manager, Rafael Center*
Steve Clarke, *Supervisor, FirstStep*
Michelle Coffin, *Supervisor, Rafael Center Case Management*
John Dinauer, *Mental Health Administrator, Rafael Center*
Shelly Ebbert, *Director of Service Planning & Coordination, AFC*
Commodore Edmond, *Supervisor of Safe Start, CSLS*
Sid Groseclose*, Director of Rafael Center*
Mark Hodar, *EPOCH*
Maria McDonald, *Case Manager, FirstStep*
Fred Maclin, *Harm Reduction Specialist, CSLS*
Scott Petersen, *Safe Start, BEHIV*
Chappell Peterson, *Case Manager, FirstStep*
Matthew Silver, *Safe Start, BEHIV*
Adam Snow, *Case Manager, Rafael Center*
Deborah Steinkopf, *Executive Director, BEHIV*
Bill Streepy, *Case Manager, Rafael Center*
Donna Strong, *Case Manager, Rafael Center*
Linda Traeger, *Executive Officer, TIA/CC*

Sponsor

Funding for this project was provided under special projects of national significance category of the Housing for People with AIDS program of the U.S. Department of Housing and Urban Affairs.

Material from the Safe Start Project Eighteen Month and Two-Year Evaluation Reports was used with permission from the AIDS Foundation of Chicago.

The Mid America Institute on Poverty

The Mid-America Institute on Poverty (MAIP) is the research and policy division of Heartland Alliance for Human Needs & Human Rights. MAIP conducts research, policy analysis, and advocacy, which facilitate the identification and illumination of emerging poverty issues and the development of solutions. MAIP facilitates and participates in community planning and organizational efforts directed toward collaborative approaches to problem solving.

MAIP can be reached at
208 S. LaSalle, Suite 1818, Chicago, IL 60604
Telephone: (312) 629-4500, extension 4525
Fax: (312) 629-4550
E-mail: maip@enteract.com

PURPOSE AND OVERVIEW

The Mid-America Institute on Poverty has conducted research, in conjunction with the AIDS Foundation of Chicago (AFC), on three different models of services for people living with Human Immunodeficiency Virus (HIV) or Acquired Immunodeficiency Syndrome (AIDS) who are also low-income, substance[1] users and are homeless or at risk of becoming homeless. This review of intervention modalities is intended to document what is being done in Chicago to serve this population, illuminate what is known about outcomes for those receiving services and suggest areas for further investigation. The three service models researched are:

- the general case management program run by the Rafael Center of Travelers & Immigrants Aid/Chicago Connections (TIA/CC) (hereafter referred to as Rafael Center)

- the FirstStep residential recovery congregate housing program operated by the Rafael Center of TIA/CC (hereafter referred to as FirstStep)

- the Safe Start scattered site, supportive housing harm reduction program run jointly by Better Existence with HIV(BE-HIV) & Community Supportive Living Systems(CSLS) (hereafter referred to as Safe Start)

Two of the programs, FirstStep and Safe Start, arose out of the Chicago Eligible Metropolitan Area (EMA) Five-Year HIV/AIDS Housing Plan. The goal of the plan was to establish a strategy to expand the availability of a comprehensive continuum of HIV/AIDS housing services in the Chicago EMA. Surveys were sent out to 3000 people identified as having HIV/AIDS; 828 people responded. The respondents were asked what was most important to them about where they live. The most important feature indicated by the number of responses, was affordability. Other features listed as important include living in one's own place, living close to friends and supports, clean and sober living environments, and housing without alcohol and drug rules. Service providers were also surveyed and they identified the most frequently occurring barriers to finding housing for their participants. The top four barriers identified are the high cost of housing, participants' history of substance use, participants' chronic homelessness, and the shortage of housing with supportive services. FirstStep and Safe Start were designed to address some of these barriers and needs within the housing system. The Rafael case management program is included here as a comparison to help illuminate what effect, if any, the different housing components have on quality of life.

The three programs studied here target people who differ in regards to how much and how often they use substances, how long they have used, and their current status in terms of use, non-use, abuse, dependence or abstinence. FirstStep participants are in the early stages of abstinence and have indicated a willingness to enter treatment. Rafael Center does not restrict its services to substance users: they serve people who are actively using, others who are in recovery and others who do not use. Safe Start's participants are active substance users or dually diagnosed (use of substances coupled with a diagnosis of a mental illness). Despite these differences in target populations, each program has the over-arching goal of enhancing participants' quality of life.

This report describes each of the three programs, profiles the characteristics of their participants, and assesses preliminary intervention outcomes as indicated by ten quality of life measures which encompass social, physical, sexual, and mental functioning of participants. **Table 1** is a summary of the general program services and their target populations. While there is overlap in some areas of the table, for example in the target population section, this study focuses on the differences.

1 The term *substance* as used throughout this report includes alcohol, marijuana, opiates, crack, cocaine, hallucinogens, stimulants and depressants and does not include nicotine or caffeine.

Table 1: Program Profiles	Rafael Center Case Management	FirstStep	Safe Start
Philosophy	*General Case management*	*Abstinence-Recovery*	*Harm Reduction*
Target Population			
HIV+/AIDS	x	x	x
Low-income	x	x	x
Homeless/At Risk	x	x	x
Mental illness			x[2]
Substance Use		x	x
Primary Services[3]			
Housing		x[4]	**X**[5]
Case Management	**X**	x	x[6]
Recovery support		**X**	
Daily Programming		x	
Duration of Program	on-going	6 to 12 months	On-going

Data for this research came from the following sources:

- program participant case files (accessed with the written consent of participants);
- longitudinal data from the administration of the Multidimensional Quality of Life Questionnaire for Persons with HIV/AIDS (MQOL-HIV), developed by New England Research Institutes. This tool measures outcomes along ten indicators of well being;
- AFC's ongoing evaluation of BE-HIV/CSLS Safe Start program which also utilized the MQOL-HIV. Parts of the AFC's evaluation are incorporated here; and
- focussed interviews with Safe Start and FirstStep staff regarding issues of program implementation.

The findings produced from this research illuminate the similarities and differences among the three programs examined. We found both similarities and differences among characteristics of populations served, program features and requirements, program enrollment and completion rates, and quality of life outcome measures. While the outcome findings are limited in that the sample sizes are small, they serve as preliminary data for

2 Mental illness is a not requirement for the Safe Start program but the program is equipped to serve those with a mental illness or people who have a dual diagnosis (a mental illness coupled with substance use).
3 In the primary services section, the '**X**' indicates the fundamental service and the small '**x**' indicates ancillary services.
4 The FirstStep program provides congregate housing, which is housing that does not provide private baths or private cooking facilities. All FirstStep participants reside in the same building and share facilities. This is a transitional housing situation in that there is a time limit on the length of stay and participants are required to participate in treatment program.
5 The Safe Start program provides scattered site housing, that is individual apartment units that are scattered throughout an area of the city and are not all in one building. In addition, Safe Start's units are permanent housing, which is defined as housing that does not place a limit on the length of residency.
6 The Safe Start program provides intensive case management services. Intensive case management, as opposed to non-intensive case management, involves a higher frequency of contacts, a low case manager/participant ratio (in this case 8:1), and more services provided by the case managers.

program development and shaping future research.

BACKGROUND

There is a dearth of empirical literature examining interventions for people who are homeless substance users, let alone people who are also HIV positive or who have AIDS. This section highlights literature with aspects that may be relevant but does not, as a whole, specifically address the issues of this population. Most of the literature is from the substance abuse field but is not specifically about people who are homeless or people who are HIV positive. Finally, almost all the research has focussed on abstinence-based programs, which is not particularly relevant for Safe Start or Rafael Center.

The use of quality of life measures in this study as a way to look at outcomes is rooted in the current debates about using abstinence as the primary criteria of success for substance use services. The recent expansion of the substance use service continuum to include services targeted at people who are using brought an expansion in the goals of services (Sorge, 1991). There is considerable movement in the evaluation field regarding the assessment of these services in terms of multiple outcome variables. Sandra Anderson (1983) describes this trend as a need to examine broader dimensions of outcome, which include total life adjustment and adaptation. Yet, even before this, clients in recovery programs expressed goals that exceeded abstinence. One study found that alcoholic patients seek more from treatment than simply ending their alcohol or drug dependence; they also want psychological counseling, school and job counseling and guidance and recreational guidance (Duvall et al, 1980).

In addition to looking at quality of life measures we will also look at the length of time participants spend in the programs. This is based on consistent findings of the 'time-in-treatment' effect from many research efforts including the Drug Abuse Reporting Program (DARP) that had 44,000 clients from 1969 through 1974. DARP found that clients who stayed in an alcohol or drug treatment program less than ninety days did no better than clients who solely engaged in detoxification services, but for those who stayed more than ninety days, improvement was directly related to length of stay (Pickens et. al, 1991).

Just as looking at quality of life issues is central to this evaluation, so is looking at how each program structures its intervention to meet the needs of their particular target group. Each of these three program interventions is directed at populations who differ in regards to their degree of use, ranging from no substance use to substance abuse. This targeting is based in part on the variation in readiness to change behavior found among substance-using individuals. Prochaska and DiClemente (1992) outline five stages of change applicable to changing addictive and other behaviors: precontemplation, contemplation, active change, maintenance, and relapse. Importantly, different intervention strategies may be appropriate at each stage (Carey, 1996 p. 293-294) especially because there is a difference between motivation for treatment and readiness to change (Fisher & Fisher, 1992).

The case management model of Rafael Center is not specifically targeted at those who are substance users but it is part of the continuum of care of services provided to this population. Case management services are integral to service provision for substance users of all types, including those who are actively using and those who are abstinent. The Institute of Medicine (1988) found that treatment approaches targeted toward those who are homeless and are using alcohol and/or drugs must address multiple, interrelated needs to be successful (i.e., alcohol and/or drug treatment, housing, health care services, employment services, etc.). A person who is homeless and an alcohol and/or drug user is unlikely to benefit from an approach that does not include a full range of services.

The residential recovery model of FirstStep is based on research about services for people who are both homeless and substance users. FirstStep combines housing with on and off-site 12-step, therapy and educational groups to provide both a clean and sober environment as well as the tools that will support participants in living independently in any type of environment upon program completion. Thomas, et al (1990) found that those who achieve a stable housing situation, even if they are HIV positive, appear to have a somewhat better chance of

remaining drug free long term. And, as described by Kate Carey, Ph.D., in her research on outpatient substance use reduction, personal efforts to change substance abuse behaviors must be paralleled by social/environmental changes that support abstinence rather than substance use. Neither component alone is sufficient for lasting change to take place. Shipley, et.al, (1982), in their documentation of treatment services, found that the probability that a client will experience a consistent treatment philosophy increases if the program controls both the treatment situation and the housing. The value of this for the participant is reinforcement of basic recovery principles, fewer mixed messages and in general, a more in depth recovery experience. This is the case at FirstStep where the housing and the structure of the recovery program, including in-house groups, are controlled by the FirstStep staff.

The harm reduction model of Safe Start promotes low threshold access to services as an alternative to traditional high threshold approaches where there are many conditions placed upon potential applicants prior to program entry. For example, most housing programs require abstinence from use of all drugs and alcohol and often do criminal background checks. This raises the threshold in terms of who can enter the program. In the Safe Start program, housing is provided as the first and foremost service regardless of whether a person is actively using. The program's philosophy is that abstinence can be included as an ideal end-point along a continuum ranging from excessively harmful to less harmful behavior but it is not a requirement of the program. This model shifts the focus of the intervention away from drug use itself to the consequences or effects of addictive behavior. Harm reduction as a model has been presented by Edith Springer as a spectrum spanning all aspects of life which includes HIV related interventions, ancillary interventions, and drug use management interventions. A copy of this spectrum can be found in **Appendix 1**.

BEHIV and CSLS have implemented the harm reduction model in slightly different ways. Both agencies rely on ancillary interventions and HIV-related interventions. Ancillary interventions include provision of housing, linkage to entitlements, and referrals to or provisions of a wide spectrum of care. HIV-related interventions include promotion of safer sex, referrals to HIV-related medical care, and safer techniques for injection drug users. BEHIV has incorporated the drug use management intervention as well by teaching safer drug use techniques and encouraging more responsible drug use. CSLS primarily utilizes drug use management interventions when the residents of their apartments seek support in this area.

Each of these models relies on an interaction between differing levels of personal motivation, commitment and effort on the part of the target populations with the environmental supports provided by the programs that promote an enhanced quality of life. The following program description section includes a description of the types of environmental supports offered and offers insight into the population served and their motivations for enrolling and participating in these programs.

RESEARCH DESIGN & IMPLEMENTATION

This research was not structured to be a formal comparison between programs. We did, however, include the Rafael Center Case Management program as a pseudo-control group. All of the programs offer general case management services but Safe Start and FirstStep provide different types of housing coupled with the case management services. The inclusion of Rafael Center was done with the intent of illuminating what effect, if any, the housing components had on quality of life. The sample is comprised of a group of participants from each program who consented to participate in this evaluation. We did not randomly sample as the program sizes were too small; instead we included all current participants and any former participants we could locate. After the sample was set we attempted to collect similar information across programs. We read participant case files, interviewed staff and administered a quality of life questionnaire to participants at two points in time. Details about the composition of the sample and the data collection methodology are expounded upon below.

The Sample:

Table 2 shows the breakdown of the sample sizes by program.

Rafael Center: The Rafael sample was chosen from the list of active case managed participants at the time this research began. Initially the sample was the entire list of case managed participants (not including former FirstStep participants or DORS participants) but some cases were closed before signing a release of information, one person refused to take part in the evaluation, while others were unavailable during the research period. (N=56)

FirstStep: The FirstStep sample was drawn from two subsets of those enrolled in the program:

- Group 1: Any one who entered FirstStep during the period of this research or who was in the program when the study started. This group will be referred to in the outcomes analysis as *FirstStep* (N=31).
- Group 2: Anyone who has ever been at FirstStep since the program inception and has left the program before the beginning of the study. This sample is primarily comprised of participants who continued on in Rafael Case Management after leaving FirstStep since those who did not continue on at Rafael Center were extremely difficult to contact. This group will be referred to in the outcomes analysis as *Former FirstStep* (N=16).

Safe Start: The Safe Start sample consisted of all participants enrolled in the program in the two year period between January 1996 and January 1998. (N=40)

Data Collection:

1. Data collected from Rafael, FirstStep and Safe Start program participant files included:

- demographic information (age, gender, education,)
- substance use history
- housing and health baseline data
- information about participants support systems
- contacts with program staff

2. Outcome data collected from participants during evaluation period included:

- Measures in ten quality of life areas as captured by the Multi-Dimensional Quality of Life Questionnaire (MQOL-HIV). The MQOL-HIV was developed by the New England Research Institutes (NERI) as an easily administered, psychometrically sound Quality of Life (QOL) instrument for persons who are HIV positive or who have AIDS. It is intended to be sensitive enough to discriminate QOL differences between

different medical interventions and to detect important changes in QOL status over time. NERI (1994) describes it as an instrument that is multidimensional, that includes subjective and objective indicators of well-being, and that focuses on aspects of QOL most likely affected by HIV/AIDS or its potential treatment.

- The ten quality of life measures (domains) captured by the MQOL-HIV are mental health, physical health, physical functioning, social functioning, social support, cognitive functioning, financial status, partner intimacy, sexual functioning and medical care. A summary QOL measure can be obtained with a formula using the scores on the mental health and physical functioning domains. Domain scores range from 4 to 28, with the higher scores indicating a more favorable assessment of the domain.[7] The questions asked to assess each domain are listed in **Appendix 2**.

3. Information collected through interviews of program staff included:

- program and model descriptions
- implementation issues
- administrative issues

Table 2: Sample Size & Data Collection Breakdown

Data type	FirstStep N=31	Former FirstStep N=16	Rafael N=56	Safe Start N=40
MQOL-HIV *baseline*	30	16	56	41
MQOL-HIV *time 2*	14	7	23	20
# used in analysis	**14**	**0**[8]	**23**	**41,20**
File Data	**31**	**16**	**49**	**46**

Data collection time line:

Data collection for Rafael and FirstStep occurred from December 1997 through August 1998.
The data for Safe Start was collected at three points: December 1996, August 1997 and January 1998.

Base line MQOL-HIV

- **Rafael Center:** administered to people in the program when the study began
- **FirstStep:** administered to participants in the program when the study began and to entering participants at intake
- **Safe Start:** administered to entering participants at intake

Time 2 Follow-up MQOL-HIV:

- **Rafael Center & FirstStep:** approximately 2 month MQOL-HIV intervals from the time the *baseline* data was gathered.
- **Safe Start:** 6 months from the time the *baseline* data was collected

We knew at the initiation of the data collection for *FirstStep* that many FirstStep participants do not stay as long as six months and therefore we started the follow-up data collection much sooner -- at two month intervals. In an attempt at consistency we then proceeded to collect *Time 2* information at two-month intervals for *Former FirstStep*

7 Domain scores were only calculated when a participant answered all four questions for the domain. If any questions were left incomplete that individual received no score on that domain and they were not included in the mean score.
8 We do not present the MQOL-HIV results for the Former FirstStep sample in this report because only seven participants in this group took the follow-up MQOL-HIV; this is too small of a sample to draw conclusions from. It is interesting to note that their scores increased over time for all ten domains.

& *Rafael* as well.

METHODOLOGICAL & DESIGN CONCERNS

1. Data Collection & Analysis:

There are gaps in the data collection. **Table 2** shows the breakdown of the sample sizes for each form of data collected in an attempt to represent the gaps in data. The primary gap occurred because nearly half of participants in all three programs who took the MQOL-HIV at *baseline* were not available at the follow-up MQOL-HIV. In an attempt to make the best comparison possible, we chose to only look at results for FirstStep and Rafael Center participants who completed both *baseline* and *time 2* questionnaires. The exception to this is Safe Start; the Safe Start data represents two different sample sizes. The decision to compare equal sample sizes (N's) for FirstStep and Rafael Center outcomes was made after the Safe Start evaluation was completed.

2. Participant Data:

A standard intake form was not used across programs so we had to draw from data already collected at each program. Each of the programs has a different emphasis and collects different types and intensities of information. The participant background data presented here varies by program, hence a comparison between programs based on background data aside from basic demographic information is largely infeasible.

3. MQOL-HIV:

- It is not possible to compare the MQOL-HIV results across programs as the baseline data collection points are radically different for each group. For example, Rafael participants may have been receiving case management for years prior to the collection of the baseline data while we know that for FirstStep participants this is the beginning of the intervention.
- Program staff expressed concerns about the relevance and validity of using this instrument to measure outcomes with the marginalized populations they serve. The instrument was tested during its development phase with HIV positive volunteers who were recruited at a hospital and a community health center. The majority of the test sample was male (70%) and Caucasian (80%). Information on income and housing status were not provided in the instrument manual. While the three programs examined here have a similar gender composition, the race of the programs' participants is overwhelming more African American than the instrument development sample. What this means is not clear, but these significant differences in sample population should be kept in mind when interpreting the results.

4. Other Methodological Concerns:

- *Small Sample Sizes:* there is uncertainty of results due to the fact that the sample sizes are quite small. It was not possible to obtain an adequate sample size at this time due to the size of the FirstStep and Safe Start programs (program capacity is 15 at FirstStep and 24 at Safe Start). With such a small sample, there is a strong likelihood that the outcomes found are due to chance.
- *Different Stages of Implementation:* Data was collected from three programs that are at radically different stages in their program implementation. Safe Start data was collected at two points in the first two years of the program. FirstStep data was collected during the first twenty months of the program. Rafael data was collected after the program had been running for over ten years. This further limits the efficacy of comparing the results of one program to another.

Rafael Center Case Management

Overview of the Program:

Rafael Center provides comprehensive HIV/AIDS services to people isolated due to poverty and displacement and seeks to improve participants' quality of life by delivering personalized and compassionate services in case management, housing and adult day health programs. Rafael Center began providing case management services to homeless persons living with HIV or AIDS in 1986. The case managers provide a multitude of services. They

- link participants to government benefits and entitlements
- connect participants to medical and oral health care through Chicago Health Outreach
- refer participants to housing & rent subsidy options
- provide participants with counsel and assistance for improving capacities of daily living
- arrange in-home care for disabled participants through the Illinois Department of Human Services Department of Rehabilitation Services (DORS).

Model & Structure:

Each case management program participant is assigned to a single case manager who is his or her central point of contact and who handles all of his or her work. Each case manager carries a caseload of approximately 50 participants. Case management contacts occur as needed (as determined by participant and case manager) with a minimum of one contact per month. The average number of case management contacts per month was approximately 2 for the sample studied here. These contacts and the work done by the case managers and participants in between meetings are the crux of this intervention.

These contacts often consist of the case manager assessing the participants' needs and then making a plan to get those needs met which may include making a referral to another agency, filling out paperwork, making a plan of action, and providing support. Case managers often make referrals to health clinics, doctors, dentists, as well as linking participants with housing resource staff and agencies, and assisting participants in accessing and filling out public aid applications.

Discharge from the case management program occurs if the participant refuses services, is non-compliant with his or her service plan, is out of contact with his or her case manager for an extended period of time, commits acts of violence or threats (with the likelihood the threat will be acted upon) against staff or program participants, or if problems of environmental safety are determined to threaten the well-being of a participant or staff members.

Participant Information:

Case management participants are referred to the program primarily by the Northeastern Illinois Case Management Cooperative coordinated by AFC, by alcohol and drug treatment programs and by health care providers. The majority of participants are asymptomatic HIV positive (53%) but one third (29%) have AIDS. At the time of this evaluation, an average of three years had passed since the participants were diagnosed as HIV positive (with a range of less than one year to sixteen years).

The program is primarily serving men (97%) who are either African American (43%) or Caucasian (47%) and between 30 and 49 years old (86%). The majority of the participants has some income at intake (56%) and has at least a high school diploma (88%). Finally, approximately one quarter of the participants (21%) has been diagnosed with depression and a few participants have other psychiatric diagnoses (7%). **Table 3** gives additional demographic information.

Table 3: Rafael Center Program Participant Demographics	**N = 49**
Gender	
Male	96%
Female	4%
Race	
African American	43%
Caucasian	47%
Hispanic	10%
Age	
Less than 20 years	0%
20-29 years	5%
30-39 years	48%
40-49 years	38%
50-59 years	5%
60-69 years	4%
Monthly Income	
$0	44%
$1-250	2%
$251-500	25%
$501-1000	27%
> $1000	2%
Education	
Less than a high school diploma/GED	22%
High school diploma/GED	32%
Some college	35%
College degree	9%
More than a college degree	2%
Ever Arrested	
yes	60%
no	40%

Of those who had an income at the time of intake, one quarter (25%) received Supplemental Security Income (SSI), a few (11%) received Social Security Disability Insurance (SSDI), nearly one third (28.5%) received SSI and SSDI, and the rest received income from work (28.5%) or other sources (7%). Half of all the participants sampled received foodstamps. Of those participants with no income, more than half (66%) have cases pending for SSI or SSDI. The rest were linked either to benefits or to employment soon after enrollment in the program through work with their case managers.

Only a small number (17%) of Rafael participants were enrolled in an alcohol or drug treatment program[9] at the time of intake into Rafael Center while over one third of the participants (39%) had been enrolled in some level of treatment in the past. Their substance use history differs considerably from that of the FirstStep and Safe Start participants in that over one quarter of them (21%) had not used any substance in at least the year prior to entering the program and the majority used one or two substances in that year (only 17% used more than 2 substances). This confirms that substance users are not the primary population this program is targeting. See **Table 4** for more detail.

Table 4: Rafael Substance Use History at Time of Intake	
# of Substances Used in the Year Preceding Intake(including alcohol)	
0	21%
1	38%
2	24%
3	12%
4	5%
Enrolled in Alcohol/Drug Treatment at Intake	
Yes	17%
No	83%
# of Past Treatment Attempts	
0	63%
1	16%
2	11%
3	5%
7	2%
>or = 10	5%

Quality of Life Outcomes:

The MQOL-HIV results for the Rafael sample are limited in that only half of the participants completed both baseline and follow-up questionnaires. This is due in part to the reality that case managers could not always guarantee in person contact with a participant at the two month MQOL-HIV follow-up due to the nature of the contacts, the nature of the participants and the size of their case loads. This limited the number of follow-up MQOL-HIV scores collected to those who consistently kept up with their case management meetings. The results may represent only a subset of the population served in this program, though one can only speculate in regards to the traits of this subset. They may be people who are worse off in terms of outside supports, or health or they may be people who are more organized and who prioritize appointments. In addition, the small sample size limits the interpretation of the results.

Average scores of participants on the Multi-Dimensional Quality of Life Questionnaire for Persons with HIV are shown for each domain in **Table 5.** Given the above mentioned concerns regarding the sample, it is interesting to note that Rafael Center Case Management program participants made small gains in quality of life in the areas of mental health, physical health, sexual functioning, and medical care. Gains of greater magnitude were made in the areas of social support, and financial status. It is not possible to claim causality in terms of what led to these gains, but one can consider aspects of the program that may have contributed to these outcomes.

9 Alcohol or drug treatment programs as referred to in this report include detoxification services, inpatient treatment and outpatient treatment.

- Because the staff places an emphasis on linking participants to a broad range of health care services, it is not surprising to see gains in the areas of physical health and medical care.

- The program is also set up to immediately address participants' financial concerns, especially by linking to and mediating with the Social Security Administration and the Department of Public Aid. This emphasis, coupled with the length of time participants' stay in services, may contribute to the gains in the financial status domain.

Table 5: Mean MQOL-HIV Scores for Rafael	**Baseline N=23**	**Time 2 N=23**	**published norms**
Mental Health	17.38	17.86	17.26
Physical Health	19.62	20.14	21.78
Physical Functioning	18.32	17.64	22.51
Social Functioning	20.5	19.27	19.89
Social Support	20.5	21.45	22.11
Cognitive Functioning	21.59	20.29	21.1
Financial Status	18.6	19.05	20.18
Partner Intimacy	20.09	19.25	20.79
Sexual Functioning	18.1	18.23	17.27
Medical Care	21.14	22.05	22.27
Summary Index [10]	59.86	53.36	57.03

- The gains in social support and mental health may result in part from the nature of case management and the holistic nature of the services provided, though this is difficult to determine.

- Finally, the gains in sexual functioning may result in part from educational components of the program, though, as with all of the above, this can only be determined through further research.

Declines in quality of life measures occurred in the areas of physical functioning, social functioning, cognitive functioning, and partner intimacy. Some of these declines appear as anomalies in light of the domains that saw gains:

- Why was there an increase in social supports but a decline in social functioning and an increase in sexual functioning but a decrease in partner intimacy? Social functioning and partner intimacy domains measure relationships on a more personal level, while social support measures something that exists outside of the person. It is possible that the educational components of the case management relationship may lead to an

10 Summary Index is a single summary measure for overall quality of life and is computed by the following formula: MQOL-HIV index = (2* Mental Health domain score) + Physical Functioning domain score.

increased awareness of actual conditions and alternatives, causing a person to rate such things as partner intimacy and social functioning lower than they had before enrolling in the program.

- Are the decreases in cognitive functioning and physical functioning linked to the course of the illness? Or are these related to the increased demands placed on participants when they enroll in the program? The increased demands, such as number of appointments, paperwork and expectations, of the case management relationship may alter the participant's perceptions about their functioning levels relative to their experiences prior to enrolling in the program.

This discussion of explanations for the increases and decreases in quality of life is speculative, however we are hopeful that this discourse will lead to enhanced research efforts. As mentioned above, and as will be mentioned throughout this report, the sample sizes were too small to make clear determinations about these outcomes. Further research efforts should seek additional data to further explicate these findings and focus on the domains that declined in order to adjust aspects of the program to better enhance these areas.

Program Enrollment and Retention:

This case management program is designed to provide on-going support for participants over a long period of time – participants are encouraged to remain in the program as long as it provides benefits to them. The average enrollment time for participants in the sample was 27 months with enrollment time ranging from 10 months to 68 months. However, it should be noted that this might reflect the bias of the sample. This bias occurred because we were only able to obtain data releases from those currently enrolled and because of the lengthy process of dis-enrollment for case management participants (case managers may wait several months to terminate a participant as often participants re-appear for services after a lengthy period of time of not coming in to Rafael Center).

Summary:

The Rafael Center Case Management program provides a wide range of services intended to meet a variety of their participants' needs. Its mission is to provide comprehensive HIV/AIDS services to people who are low income; the program does not target those with substance use issues and about one-quarter of their participants' report using no substances. Each participant is assigned an individual case manager with whom they meet face to face at least once monthly and have additional phone contacts and meetings as needed.

The participants sampled here stay in the program for long periods of time. This may indicate some level of satisfaction with the services provided and with the manner in which they are provided, and may also indicate that the program is targeted toward a population suited to these services.

Participants who took the MQOL-HIV at the two-month follow-up point had small gains in quality of life in the areas of mental health, physical health, sexual functioning, and medical care and gains of greater magnitude in the areas of social support, and financial status. Further discussion and research should look at bolstering the parts of the program that may be contributing to these gains and more importantly figure out how to strengthen areas of the program that might be contributing to the domains that declined.

FirstStep

Overview of program:

FirstStep is a residential recovery program located in the Uptown neighborhood on the north side of Chicago. The program began in April 1996. It was developed in an effort to address the substance use recovery, housing stability and HIV related health status of people who are homeless and low income living with HIV or AIDS as identified in the Chicago Five Year HIV/AIDS Housing Plan. It is funded through a federal Housing for Persons with AIDS (HOPWA) demonstration grant.

FirstStep is set up in a congregate housing format. All of the program participants reside in the same building and share bathrooms, cooking facilities, and common areas. In addition this housing is transitional in that there is a maximum length of stay of twelve months.

Admission to FirstStep is open to persons age 18 and older who are HIV positive or have AIDS, who have been alcohol and drug free for a minimum of three days, and who are homeless. Applicants with a significant length of sobriety are not eligible. Individuals must be ready to engage in a rigorous treatment process, be willing to engage in constructive activity during his or her stay, and be committed to working intensely on recovery skills. The activities participants agree to partake in include employment, school, day programming at Rafael Center and volunteer work. FirstStep staff try to screen out people who have a serious mental illness. The program has the capacity to house fifteen persons. FirstStep participants are charged a program fee equaling 30 percent of their income and are asked to commit to the program for at least six months with a goal of staying for twelve months.

Service Model:

The program is rooted in the 12-Step model and stresses abstinence from alcohol and drugs. FirstStep staff are devoted to effecting a change in the individual, enabling him or her to return to a productive alcohol and drug free life. The program is promoted as offering a chance for renewal of life and commitment to the future. The staff at FirstStep recognize that recovery from addiction is an ongoing process and for many individuals this process requires a supportive environment and adequate time to develop a lifestyle of continuous sobriety. The three essential elements of recovery emphasized by the program are individual responsibility, a strong supportive system, and personal faith and belief in a higher power. The structure follows from these.

Structure of the Program:

- Each participant is assigned to a FirstStep caseworker. The job of the caseworker is to keep participants on track with their recovery goals. This is done through one-on-one meetings, the development of a sobriety plan and treatment contract, and general goal setting. In addition, residents may have an outside case manager who assists them in attaining medical services, insurance and the like.
- New residents are assigned to a senior resident who is responsible for acquainting new members of the house and explains all policies of the program. The senior resident also takes new residents to at least one 12-step meeting per week outside of the house.
- All participants eat supper together each weekday
- Each member of the house is a member of a group that helps them deal with changing his or her perceptions and attitudes about life.
- Participants attend at least five 12-step meetings per week, some inside and some outside the house and new participants attend 90 meetings in 90 days. Participants also attend process therapy groups, discussion

groups, education groups and community meetings. Group attendance is the central focus of this intervention.

- Discharge occurs if the participant breaks the house rules or voluntarily leaves before completing the program. Grounds for an unfavorable discharge include use of alcohol or drugs, committing an act of violence or making a threat of violence, engaging in a sexual or romantic relationship with another house member, or accumulating three strikes (strikes are acquired when someone breaks house rules). Discharge can also occur if a resident's health deteriorates to a point that they need a more supportive living environment.
- Successful completion or graduation occurs when a participant completes at least six months of the program and has made positive life changes in the directions of sobriety, health and towards leading a productive life.

Program Implementation

FirstStep and Safe Start programs were evaluated soon after their inception and a portion of the research focussed on implementation issues. Early on staff identified issues and problems in the program structure so changes were made in how the programs are run. The FirstStep program has evolved through time and its focus has shifted slightly, primarily in regard to daytime activities.

- In the beginning of the program the participants were primarily enrolled in the day program at Rafael Center. Daytime activities included groups, rehabilitative and alternative therapies including employment counseling, art therapy, and massage or acupuncture, lunch, and educational and recreational outings. FirstStep staff found that participants were not focusing their mental and physical energy on recovery-based activities so the emphasis of daytime activities was shifted towards employment, education and training or volunteer based activities.

- This focus has again shifted in response to an increase in the number of participants leaving the program prematurely because they have employment and could afford an apartment and felt ready for independent living. FirstStep staff found that while these participants may have developed the skills needed to get a job, they had not yet developed and solidified essential recovery skills, including relationships, daily structure, self control and awareness. In an attempt to maximize what FirstStep has to offer, participants are now encouraged not to seek work or training for the first few months in the program. This time is now heavily dedicated to recovery oriented programming and additional on site groups and lectures have been added as well as educational and recreational activities.

- At program inception the staff were all male and there were few successes with female participants. A female case manager was hired with the intent that this would enhance the treatment provision to female participants and increase their success rate.

Participant Information:

The majority of people who participate in FirstStep are male (72%), African American (91%) and are 30 to 39 years old (60%). One third of the participants have no income, one third have no high school diploma and over three-quarters have been arrested (79%). Nearly one third (30%) of participants had been diagnosed with depression prior to intake and a few (12%) had been diagnosed with bi-polar disorder. **Table 6** gives additional demographic information.

Of the participants who reported having income at the time of intake, half received SSI (50%) and over a third

received SSI and SSDI (38%). A small number of participants received SSDI (6%) or had income from work (6%). Nearly half of the participants received foodstamps (49%) and an overwhelming majority had a doctor at the time of intake (89%). Participants who had no income or health care were linked to these services within the first two months of enrollment.

Table 6: FirstStep[11] Program Participant Demographics		**N = 47**
Gender	Male	72%
	Female	26%
	Transgendered	2%
Race	African American	91%
	Caucasian	7%
	Hispanic	2%
Age	Less than 20 years	2%
	20-29 years	9%
	30-39 years	60%
	40-49 years	25%
	50-59 years	4%
	60-69 years	0%
Monthly Income	$0	32%
	$1-250	0%
	$251-500	40%
	$501-1000	28%
	> $1000	0%
Education		
	Less than a high school diploma/GED	34%
	High school diploma/GED	34%
	Some college	29%
	College degree	3%
	More than a college degree	0%
Ever Arrested	yes	79%
	no	21%

Table 6 shows that a large number of participants had been arrested. Most of these participants have had multiple arrests. The reason most frequently stated for arrest is in the general category of stealing, including theft, shoplifting, burglary and robbery. The second and third most commonly committed crimes are possession of a controlled substance and disorderly conduct. The fourth most common crime is assault and battery.

In regard to housing situations prior to entering FirstStep, most participants report residing in some type of in-patient treatment program and the rest were homeless. Nearly all of the participants enrolled in treatment at the

[11]FirstStep data in this table represents data collected from FirstStep and Former FirstStep participants as defined in the Research Design section.

time of intake reported having been homeless prior to treatment (see **Table 7** for more information). About the half the participants were able to remember how long they had been homeless. The majority of this group reported that the current bout of homelessness had occurred within the year prior to intake into FirstStep and the overwhelming majority (89%) reported that their homelessness resulted from their drug and/or alcohol use.

Table 7: FirstStep Substance Use History at Time of Intake	
# of Substances Used in the Year Preceding Intake(including alcohol)	
0	
1	2%
2	9%
3	24%
4	38%
5	19%
6	6%
	2%
Enrolled in Alcohol/Drug Treatment at Intake	
Yes	79%
No	21%
# of Past Treatment Attempts	
0	18%
1	28%
2	28%
3	9%
4	7%
5	5%
>or = 10	5%

Over three fourths (79%) of the participants entered FirstStep straight from alcohol or drug treatment programs, including day treatment, detoxification services and inpatient treatment. In addition, the majority (82%) of the entrants have had some previous treatment episode, most having had one or two previous treatment episodes. FirstStep participants on the whole are poly-substance users; only 11% are not. More than one third (38%) regularly used three different substances in the year prior to entering FirstStep and over one quarter (27%) used more than three substances.

Quality of Life Outcomes:

As shown in **Table 2,** a significant portion of FirstStep participants left the program prior to the administration of the two-month MQOL-HIV follow up. We only have *baseline* data for those who left, so their scores are not included in the MQOL-HIV results presented here. Not only does this decrease the sample size (requiring caution in interpretation of these results), but it also indicates that the scores presented are likely biased in that they only represent participants who stayed in the program longer and who may be different from those who left the program early. It is possible that following scores may more clearly reflect those who have benefited from the program or those who were more likely to succeed. Average scores of participants on the MQOL-HIV are shown for each domain in **Table 8.**

Given the above mentioned cautions, it is interesting to note that FirstStep program participants made small gains in physical health, social functioning, and medical care. Gains of greater magnitude were made in the areas of:

mental health, social support, cognitive functioning, and partner intimacy. FirstStep participants had more areas of significant gain in quality of life measures than did Safe Start and Rafael Center participants. Program staff assisted in the interpretation of these results by providing insight into the program operations and structure:

- The nature of the program as a congregate housing program with an extremely narrow focus on recovery may contribute to the positive gain in some of the domains listed above, including mental health, social support and social functioning. The supportive, structured environment appears beneficial in quality of life terms.

Table 8: Mean FirstStep[12] MQOL- HIV Scores

Domain	Baseline (N=14)	time 2 (N=14)	Published Norms
Mental Health	16.36	18.36	17.26
Physical Health	23	23.21	21.78
Physical Functioning	22.29	21.07	22.51
Social Functioning	19.36	19.57	19.89
Social Support	18.43	23.64	22.11
Cognitive Functioning	19.79	20.57	21.1
Financial Status	18.36	17.5	20.18
Partner Intimacy	18	21.33	20.79
Sexual Functioning	15.67	14.38	17.27
Medical Care	15.62	16.07	22.27
Summary Index	57.57	57.07	57.03

- The gains in physical health could be related to the reality that these participants are no longer homeless, have guaranteed meals and may have more regular contact with their physicians.

There was a decrease in physical functioning, financial status, and sexual functioning over time.

- The decrease in the physical functioning domain may have occurred as result of someone who was homeless having gained housing. The physical demands of the participants' daily routine are lessened once in housing, for example, they no longer have to carry all of their belongings nor stand in lines for meals and shelter beds. The staff speculate that this lessening of demands may result in a physical letdown.

The declines in financial status and sexual functioning may be explained by the structure of the FirstStep program:

- Regarding financial status, participants do not have the opportunity to earn additional income (assuming they receive government benefits) or any income (assuming they do not) for the first few months of the program. For the first several months of enrollment, participants are not allowed to hold a job so that they will focus on gaining the recovery skills needed to stabilize and maintain a clean and sober lifestyle. This may lead to decreased satisfaction with their financial status.

- Regarding the decrease in sexual functioning, no sexual or romantic relationships are allowed between

12 FirstStep data in this table represents only data collected from current FirstStep participants, not former FirstStep participants, as defined in the Research Design section.

housemates and outside sexual relationships are made difficult due to the structured nature of the program (structured schedules, no overnight-guest policies). In contrast there was an increase in partner intimacy that may be linked to the program model's emphasis on communication and honesty.

Program Enrollment and Completion

As of September 1998, 84 people had enrolled the program since its inception in April of 1996. Data was collected from 47 of these participants. Of these 47, 41 had left the program as of 8/1/98. Of these, over one third (33%) successfully completed the program, only one participant (2%) partially completed the program and over two-thirds (65%) were discharged before program completion. This completion rate appears high relative to other programs cited in the literature. Stark (1992) reports a completion rate for therapeutic communities of up to 24% and a completion rate of outpatient programs ranging 15% to 20%.

FirstStep is a structured program with a definitive completion sequence at which time participants theoretically have obtained the skills they need for independent living and continued recovery. Successful program completion indicates that the participant has successfully achieved all or the majority of their goals as delineated in the individual treatment plans, that they have a stable housing situation to move into, and that they have remained clean and sober.

Table 9 shows the detail of why the 26 participants were discharged before program completion.

Table 9: Reasons for Discharge before Program Completion

FirstStep Participants		**N=26**
Left Voluntarily:	specifics not given	0%
	departure without notice[13]	15%
	self-discharge before ready[14]	19%
	Total:	**34%**
Asked to Leave:		31%
relapse		
	inappropriate behavior[15]	12%
	non-compliance with program rules[16]	23%
	non-payment of rent	0%
	Total:	**66%**
Unknown Reasons		**0%**
Death		**0%**

13 *Departure without notice* generally refers to participants who left the physical premises of the program one-day to go about their routine but who failed to return and have not contacted the program again.

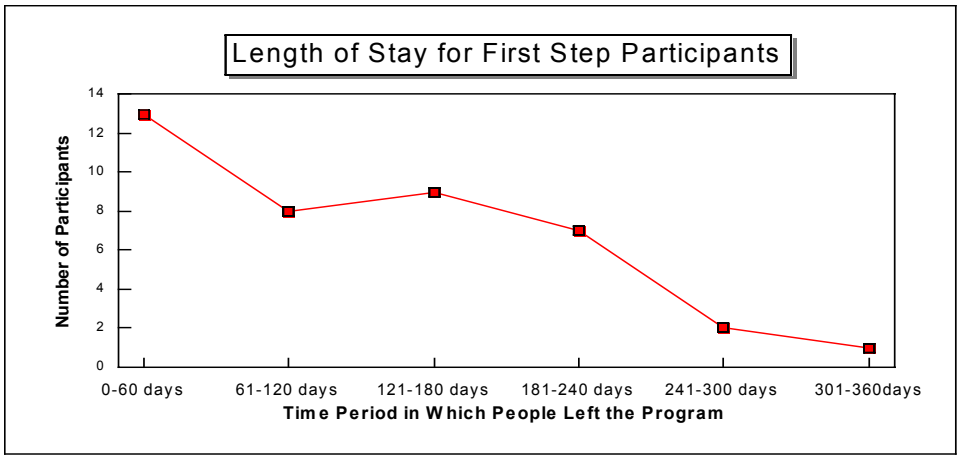
14 *Self-discharge before ready* refers to people who notified staff of their intentions to leave the program but staff advised against the move. Generally these participants had not been in the program long and had not benefited from all the program has to offer. Also, staff generally believed that this group was in early stages of recovery and had not had time to solidify some crucial recovery skills such as forming new relationships and coping mechanisms for situation in which substances are present or being offered.

15 *Inappropriate behavior* includes but is not limited to harassment of fellow program participants, lying and fighting.

16 *Non-compliance with program rules* includes not returning by curfew, not attending groups, non-compliance with social service or group requirements, selling legal or illegal items on the premises, allowing people not enrolled in the program to stay over, and a refusal to thrive or attempt to engage in the program.

Just as the breakdown of reasons participants are discharged offers insight, so does the length of time people stay in the program. The average length of stay for FirstStep participants was five months with over one third (35%) of the participants leaving the program within two months of enrollment. The majority of those that leave within the first two months have relapsed. In fact, of the eight people who have left the program due to relapse, seven had relapsed in the first two months. Many FirstStep participants entered the program in the beginning days of their abstinence which can be a particularly unstable time with a high risk of relapse. The length of stay for the FirstStep sample is represented in **Graph 1.** Literature on general substance abuse treatment indicates that with outpatient programs up to 80% of clients drop out by the end of the first three months (Stark, 1992; Baekeland and Lundwall, 1975). A few studies on inpatient programs found that up to half of inpatient clients' drop out within one month of entering the program (Gordis et. al 1981). Though FirstStep is not an outpatient program and is not a traditional inpatient program, these studies offer some basis for interpreting the meaning of FirstStep's dropout rate.

Graph 1: Length of Stay Breakdown for FirstStep Participants since Program Inception



Very few participants (7.5%) stay for longer than eight months. Once a participant has been in the program for four months, their likelihood of successful completion greatly increases and by six months nearly all that are left in the program complete it.

Summary

FirstStep is first and foremost a recovery program with a secondary housing component. The program serves only those in the very early stages of recovery. Its mission is to help participants achieve the skills they need to make progress in their recovery and it achieves this through an emphasis on group attendance and community.

The FirstStep population appears to have serious substance use issues which are coupled with, and in many cases have led to, homelessness and criminal histories. What is significant about this group is that the majority had entered treatment programs in the past and most came to FirstStep directly from treatment. They appear ready to seriously undertake a rigorous treatment program as provided by FirstStep.

When looked at in terms of outcomes as measured by the MQOL-HIV, after taking into account the extremely small size of the sample, FirstStep participants who remained in the program longer than two months appear to be faring well for the most part. Participants have experienced extremely significant positive changes in mental

health and social supports. Elements of the program, target population, or environmental factors that contribute to these areas should be identified and examined.

FirstStep participants are very likely to leave the program before completing (estimated to occur between six and 12 months but differing based on individual progress) --two thirds (67%) leave before successfully completing the program. Most who did not complete the program were discharged --the majority because of relapse or non-compliance with program rules. Engaging participants in the first two months of the program appears crucial in terms of preventing relapse and promoting successful program completion.

Safe Start

Overview of the Program:

The information for this section is based on the Two Year Evaluation Report (Kuehnert, 1998) and from discussions with staff at AFC, BE-HIV and CSLS.

Safe Start is an inter-agency collaboration initiated and coordinated by the AIDS Foundation of Chicago (AFC) in partnership with two community-based social service organizations, Better Existence with HIV (BE-HIV) and Community Supportive Living Systems (CSLS). BE-HIV operates scattered site units in the northside neighborhoods of Edgewater and Rogers Park and CSLS operates scattered site units in the southside neighborhoods of South Shore, Kenwood and Hyde Park. Safe Start was funded by the U.S. Department of Housing and Urban Development with a 3-year supportive housing program grant award in July 1995. Safe Start began providing program services in January 1996.

The purpose of Safe Start is to provide supportive, permanent housing (no limit on the length of residency) to homeless men and women with HIV infection and concurrent disability due to current substance use and/or mental illness. This meets a housing need identified in the Chicago Five-Year HIV/AIDS Housing Plan. The project has the capacity to serve 24 participants at any one time. Safe Start seeks to achieve its purpose by providing its services using harm reduction as a guiding philosophy. Participants are provided with housing in scattered, individual apartment units and receive intensive case management. Through case management participants have access to an extensive network of medical and psychosocial support services. Participants are required to pay a monthly program fee of 30 percent of their monthly income. The initial reason many participants enter the program is to secure housing.

Program Model:

Safe Start is first and foremost a housing program that is based on the harm reduction model of treatment. Staff report that the participants' self image and sense of personal empowerment is enhanced by the use of scattered site housing. This may be related to the fact that living in independent housing units in a community setting is the norm in this society. Staff report that, for participants, living in their own apartment reinforces a sense of ownership and control over their life circumstances while fostering individual integration into the community.

There are a variety of components of the harm reduction model at work within this housing context. Harm reduction, as it is practiced at Safe Start, focuses on the individual's behaviors that resulted in his or her homelessness. The program management does not rely on the traditional treatment approach that requires total abstinence from substance use on the part of participants as a condition for providing housing. In addition, they remove the punitive approach in that the participant is not punished with loss of housing if he or she uses chemical substances. The Safe Start program staff seek to identify and address the underlying causes of participants' homelessness with incremental, positive changes in social behavior and life skills. This might require assisting the resident in securing medical insurance, employment skills, anger management, or anything else that addresses events and behaviors that led to the participants' homelessness. Staff tolerates substance use while developing interventions with the participants that enhance their self-sufficiency and re-integrate them into the community. Harm reduction is a very practical orientation, in that the staff emphasize assisting the participant in developing basic life skills and becoming self-sufficient with the hope that if the participant moves in the direction of self-sufficiency, they may decrease or even completely stop their substance use.

Structure of the Program:

The central component of the Safe Start model is intensive case management. The participant/case manager ratio is 8:1. Case management is provided on a team basis with each case manager kept apprised of each participant's situation and needs. The intensity of case management can vary by the frequency and type of service encounters, the duration of each encounter, and the duration of project enrollment.

- Case management encounters include home visits, phone calls, office visits, and ancillary calls or visits (those calls or visits made to other service providers on behalf or along with the participant) and include provision of a range of services. A case manager might: provide crisis intervention or counseling, provide food vouchers, transportation assistance or assistance with bill payments, make referrals to employment, training, or education, or make referrals to health providers and mental health providers.

- Participants, at a minimum, must make one monthly meeting with their case manager. The participants in this sample roughly averaged eight case management contacts per month.

- Violation of program rules and regulations may result in termination from the program. Examples of potential rule violations include having people not on the lease nor in the program occupy the unit, and the sale of any legal or illegal products or services from the unit.

Program implementation

Based on the first evaluation of Safe Start, a few changes in programming were made in year two (early 1997) of the program:

- An increase in the case manager staffing by 0.5 FT at each partner agency, decreasing the participant: case manager ratio from 12:1 to 8:1. This change is due in part to the intense demands on the case management staff related to the complex needs and demands of the project participants.

- The addition of funds to allow the partner agencies the flexibility to obtain on-site licensed clinical social worker and psychiatric consultation at their agencies or in their participants' homes.

- There has been continual refinement of the harm reduction model in order to meet the needs of the population being served. Since the concept of harm reduction is quite broad it is necessary to make revisions based on the demands of participant and program needs.

Participant Information:

The data and most of the analysis for this section was taken from the Two Year Evaluation Report (Kuehnert, 1998).

Participants are referred to the program primarily by the Northeastern Case Management Cooperative coordinated by AFC and through referrals from shelters and transitional care environments within the continuum of care of homeless resources. Of the 46 participants who have enrolled in the program since its inception, three quarters (76%) are male and the majority (94%) African American. Three quarters of the participants (75%) are between 30 and 49 years of age and three quarters (76%) had a monthly income of less than $500 at entry into the project.

See **Table 10** for additional demographic information.

Table 10: Safe Start Program Participant Demographics		**N = 46**
Gender	Male	76%
	Female	24%
Race	African American	94%
	Caucasian	6%
Age	Less than 20 years	2%
	20-29 years	15%
	30-39 years	45%
	40-49 years	30%
	50-59 years	4%
	60-69 years	4%
Monthly	***Income***	17%
$0		
	$1-250	7%
	$251-500	52%
	$501-1000	24%
Disability (All HIV +)		
	Seriously Mentally Ill	2%
	Substance User	63%
	Seriously Mentally Ill Substance User	35%

At the time of enrollment, nearly three fourths (72%) of the participants were homeless and the rest (28%) were at risk of homelessness. Additionally, the majority (63%) of the participants were disabled by chronic alcohol or other chemical addiction, over one third were disabled both by chronic addiction and serious mental illness and only one participant (2%) was disabled solely by a serious mental illness. Seven of the eight participants with no income at program intake gained entitlement income through the assistance of their case managers. Participants also have increased the number of types of assistance they were receiving, most often adding Medicaid, Medicare, SSI and foodstamps to what they had already been receiving.

In 1997 there were thirty-seven participants in the program.

- Nearly three quarters of them (70%) were actively using alcohol or other drugs at the time of program intake, six of whom (16%) were injecting drugs. After 180 days of program participation, a majority (65%) of those using reported decreased substance use. In that same period of time, five of the six injecting drug users had adopted safer needle practices and one reported complete abstinence from injecting drugs.

- One quarter of participants in 1997 reported being sexually active during the program year. After 180 days of program participation, nearly all of these participants (96%) reported use of safer sex techniques.

Quality of Life Outcomes:

The data and most of the analysis for this section was based on the Two Year Evaluation Report (Kuehnert,

1998).

Average scores of participants on the Multi-Dimensional Quality of Life Questionnaire for Persons with HIV are shown for each domain in **Table 11.** Keep in mind that the Safe Start data represents two different sample sizes as over half of the participants dropped out before the six-month follow-up questionnaire. It is likely that those still in the program at time two are different than those who are no longer in the program. Also, given the relatively small size of the Safe Start sample, as with the FirstStep and Rafael samples, it is important to be extremely cautious in the interpretation of these results.

Table 11: Mean Safe Start MQOL- HIV Scores

Domain	Baseline(N=41)	time 2(N=20)	Published Norms
Mental Health	16.02	15.58	17.26
Physical Health	13.79	14.85	21.78
Physical Functioning	18.56	17.10	22.51
Social Functioning	13.03	12.40	19.89
Social Support	18.58	17.11	22.11
Cognitive Functioning	11.69	13.61	21.1
Financial Status	14.17	13.65	20.18
Partner Intimacy	20.27	17.16	20.79
Sexual Functioning	15.12	14.17	17.27
Medical Care	17.11	16.11	22.27
Summary Index	50.17	48.26	57.03

Given these cautions, it is interesting to note that there were increases in the areas of physical health and cognitive functioning:

- The gain in physical health may be related, as mentioned with the FirstStep participants to the attainment of stable housing and linkages to health care providers.

- The gain in cognitive functioning domain scores from baseline to time 2 are consistent with reported decreased substance use by the participants over time.

Scores in all other domains decreased from baseline to time 2. Some of these decreases appear paradoxical:

- The decrease in the social support and social functioning domain scores, given the intensity of the case management aspect of the program, is paradoxical. This may be a reflection of the drastic shift in the participants' social circumstances and disruption of the participants social network given their move from the streets to their own apartment.

- In all domains, at both times 1 and 2, Safe Start participants score lower than the normative scores. This might be expected given the project's population of people who are homeless or near-homeless and participants with multiple disabilities compared to a population of HIV-affected persons from a wider array of social, economic and illness backgrounds. These differences are most pronounced in the domains of

physical health, social functioning, cognitive functioning and financial status.

Although not shown here, it is important to note that of the differences between the Safe Start participants and the normative group, between male and female Safe Start participants, or between Time 1 (*baseline*) and *Time 2* for either subgroups or for the group as a whole, only two were outside of two standard deviations from the mean score: cognitive functioning and social support.

Program Enrollment and Retention:

Nearly half of the participants (48%) have left the program in the two-year period. The majority of these were asked to leave. The breakdown of reasons participants left the program can be found in **Table 12**. For definitions of the reasons see the footnotes on page 20 and page 26. Those that left went to: alternative housing with supportive services (3), subsidized independent housing (1), unsubsidized housing (3), residing with family or friends (3), jail (1), a shelter (1) with the rest going to unknown destinations (7).

The participants have lived in the scattered site apartments an average of ten months (range of 1 to 22 months, median of 8.5 months, and a mode of 4 months). The first 60 to 90 days in housing are key to success in stabilizing in the program. During that time participants must show that they will: take care of their apartment; perform activities of daily living; follow-up on their health care; manage money; keep appointments; maintain/restore positive social support; and decrease or stabilize substance use.

Table 12: Reasons for Discharge

Safe Start Participants		**N=22**
Left Voluntarily:	specifics not given	32%
	Total:	**32%**
Asked to Leave:		
	inappropriate behavior	4%
	non-compliance with Program rules	32%
	loss of program eligibility	4%
	non-payment of rent[17]	4%
	Total:	**44%**
Unknown Reasons		**9%**
Death		**14%**

Summary:

Safe Start participants appear to be successfully making changes in their lifestyle congruent with the harm reduction ancillary and drug use management interventions. People who were homeless are now successfully housed independently, people who reported alcohol or drug use at the time of intake are reducing the amount used, injection drug users are adopting safer needle use practices and nearly all report the use of safer sex techniques. Participants also are attaining some stability in housing as shown by the length of stay data. The Safe Start program appears to be successfully providing the supports needed to reach these goals.

On the other hand, the majority of the MQOL-HIV scores for Safe Start decreased over time. While this may solely be due to chance, given the small sample size, it is worth considering why this may have occurred, especially in the social support domain. It is possible, as participants settle into the program, this score and others will increase. In the meantime, program staff may wish to pay particular attention to exploring the social support needs of the program participants and provide additional supportive services as indicated.

17 Non-payment of rent is no longer a discharge factor for Safe Start participants.

SUMMARY

These three programs serve different sub-populations within the same strata (low-income, HIV+ persons, who are homeless or in danger of losing housing). The majority of participants in the FirstStep and Step Start programs had monthly incomes ranging from $251 to $500. Rafael Center case management participants had significantly lower incomes than those in the other two programs, with 44 percent of their participants having no income at intake. In addition, Rafael Center serves a more racially diverse set of clients than do Safe Start and FirstStep, whose program participants are nearly all African American. FirstStep participants tend to be younger than those of Rafael Center and Safe Start. And finally, Safe Start and FirstStep serve more women than does Rafael Center.

The participants of these programs have differences and similarities on other descriptive variables as well. Rafael Center participants had more years of education than FirstStep participants (data not available for Safe Start). FirstStep participants were more likely to have been arrested than were Rafael Center participants (data not available for Safe Start). All three programs had significant proportions of participants (over 25 percent) with mental health/illness issues. For both the Rafael Center and FirstStep programs the most often cited form of mental health diagnosis is depression (data not available for Safe Start).

FirstStep and Safe Start participants were much more likely to be substance users than Rafael Center participants. This is not surprising given that the Rafael Case Management program does not target substance users as do Safe Start and FirstStep. These three programs intentionally serve populations that differ in regards to how often and how much they use, how long they have used and their current status whether it be active use, no use or abstinence.

- The Rafael Center Case Management program does not target those with substance use issues, with about one-quarter of their participants not using and never having entered a treatment program. Its services are available to substance users, non-users in various stages of recovery, as well as those who have never had a problem with substance abuse.

- FirstStep serves only those in the early stages of recovery and those that enter the program express a desire to engage in recovery based activities. FirstStep participants on the whole are poly-substance users; only 11 percent are not. More than one third regularly used three different substances in the year prior to entering FirstStep and over one quarter used more.

- Safe Start serves those who are actively using substances and who have experienced problems due to their addiction. Those that enter the program are first and foremost seeking housing, and only as time in the program progresses do some seek to engage in interventions addressing their substance use. Nearly three-quarters of the participants in 1997 (70%) were actively using alcohol or other drugs at the time of program intake, six of whom (16%) were injecting drugs. Many of their participants are poly-substance users.

This comparison indicates that Safe Start and FirstStep participants are similar in many ways. They differ primarily on three factors. FirstStep participants are younger, they are abstinent at the time of program entry and they are seeking a recovery program. Safe Start participants are slightly older, are likely to be using and are primarily seeking housing at the time of program entry.

The overall indications of quality of life and program completion outcomes point to a variation of strengths and challenges among program outcomes. Because this study has not identified and examined all the potential factors

influencing outcomes, we are reluctant to make proscriptions based on these findings. However, the following can be said: Safe Start appears to retain its program participants longer than does FirstStep. This may indicate that, for those target populations for whom establishing program participation is an important preliminary activity, Safe Start is more appropriate than a program such as FirstStep. For those who are willing and able to follow abstinence-based recovery rules, FirstStep appears to offer the opportunity to significantly improve the quality of participants' lives. This may be a strong program model for that population. Finally, because of the host of elements which may impact the lives of Rafael Center Case Management participants beyond the control of the program, we are unable to point to areas in which indicate strengths or weaknesses of that program model based on this study.

LESSONS LEARNED AND NEXT STEPS

While the findings point to general trends and patterns, we must caution the reader again to interpret these findings with reservation because of the small sample sizes used in the analysis (these are relatively small programs; Safe Start and FirstStep each have less than 25 participants), and the newness of two of the three programs (FirstStep and Safe Start were in their first years of operation during the data collection period). Given these precautions, however, the analysis has provided some discussion points for consideration of further research and model development.

1. The inclusion of the Rafael Center Case Management program in this study did not assist in clarifying what outcomes could have been effected by the housing components of Safe Start and FirstStep as had been hoped at the outset. This is due in part to the limitations of the research design and the small sample sizes. Further research should be designed in a manner that more effectively incorporates program features in determining outcomes.

2. FirstStep participants have experienced extremely significant positive changes in mental health and social supports. Elements of the program, target population, or environmental factors that contribute to these areas should be identified and examined for possible replication in programs such as Rafael Center and Safe Start. Such a study may provide useful lessons for other programs.

3. The FirstStep program loses a significant proportion of participants through early discharge due to relapse. Measures taken at the program level may be able to reduce this. The program has been restructured to 'front load' activities that are most likely to result in increased retention. Further research efforts could examine if these measures have been effective or could study alternative ways to increase relapse prevention. On the other hand, FirstStep has been successful relative to other programs cited in the literature in terms of program retention. Attributes of the participants and the program could be examined more closely to see what is contributing to this success.

4. Safe Start participants are experiencing extremely positive outcomes in regards to the harm reduction measures but appear to experience more quality of life losses as measured by the MQOL-HIV than do participants in the Rafael Center Case Management and FirstStep programs. More research needs to be done to pinpoint the causes (including programmatic, environmental, and population-associated) of these gains and declines.

5. Additional questions that could be addressed in further research based on the findings and limitations of this report might include the following:

- What is the relationship between program contacts (frequency, intensity and type) and outcomes?
- What combinations of resources did the participants utilize?
- What are the long-term effects of these programs? Will the population served by these always need supportive housing? Do the participants continue to experience episodes of homelessness or do they stay in housing?
- What interventions lead to enhanced self-sufficiency, increased stability in housing and improved health?
- Do the different models work better for different people and at different stages of recovery?
- Who is dropping out of the programs, why are they dropping out and what supports are in place for them once they leave?

This report describes three different intervention models and their preliminary outcomes with regard to quality of life for program participants. These findings point to strengths and challenges of each approach. Further work

needs to be done in order that particular model features can be examined for their contributions to outcomes. Data of this nature will assist in improving future intervention models.

BIBLIOGRAPHY

Anderson, Sandra, Ph.D. 1983. Group Therapy with Alcoholic Clients: A Review. In Current Controversies in Alcoholism. The Haworth Press.

Avis, Nancy & Smith, Kevin. 1994. MultiDimensional Quality of Life Questionnaire for Persons with HIV/AIDS. New England Research Institutes: Watertown, MA.

Baekeland, F and Lundwall, L. 1975. Dropping out of Treatment: A Critical Review. Psychological Bulletin, 82, 738-783.

Barry, Herbert III. 1982. Adaptive Behavior of Alcoholic Tolerance and Withdrawal. In Theodore Cicero, (ed.), Ethanol Tolerance and Dependence: Endocrinological Aspects. National Institute on Alcoholism Research, Monograph 13, Department of Health and Human Services Publication No. ADM 83-1258m 16-26. Washington, DC: GPO.

Carey, Kate, Ph.D. June 1996. Substance Use Reduction in the Context of Outpatient Psychiatric Treatment. Community Mental Health Journal, 32, No. 3.

Chicago EMA Five-Year HIV/AIDS Housing Plan. August 1995. Prepared by AIDS Housing of Washington (Seattle, Washington) for AIDS Foundation of Chicago (Chicago, Illinois).

Duvall J, Ochs B, Lorei T., Baker S. 1980. Treatment Goals of Alcohol-Dependent and Drug Dependent Patients. International Journal of Addictions, 15, 419-25.

Fenley, James. 1984. A Study of Affective States Following Alcohol Withdrawal (honors dissertation). Philadelphia: Temple University.

Fisher, J.D. and Fisher, W.A. Harm Reduction Treatment Model Specifically for Changing AIDS Risk Behavior. Psychological Bulletin, v.III, 455-474.

Gordis, E., Dorph, D. Sepe, V. and Smith, H. 1981. Outcome of Alcoholism Treatment among 5578 Patients in an Urban Comprehensive Hospital-Based Program: Application of a Computerized Data System. Alcoholism: Clinical and Experimental Research, 5, 509-522.

Institute of Medicine. 1988. Homelessness, Health and Human Needs. National Academy Press.

Kuehnert, Paul. October 1997. Safe Start Project 18 Month Evaluation Report. AIDS Foundation of Chicago, Chicago IL.

Kuehnert, Paul. March 1998. Safe Start Project 2 Year Evaluation Report. AIDS Foundation of Chicago, Chicago IL.

Lubran, B. 1990. Alcohol and Drug Abuse among the Homeless Population: A National Response. Alcoholism Treatment Quarterly, 7, #1, 11-23

Marlatt, G. Alan. 1996. Harm Reduction: Come as You Are. Addictive Behaviors, v. 21, #6, 779-788.

Prochaska, J. O. & DiClemente, C.C. 1992. Stages of Change in the Modification of Problem behaviors. In M. Herson, R.M. Eisler, & P. M. Miller, (eds.), Progress in Behavior Modification. Newberry Park, CA: Sage, 184-218.

Shipley, Thomas E. Jr. 1982. Alcohol Withdrawal and Its Treatment: Some Conjectures in the Context of Opponent-Process Theory. Journal of Studies on Alcohol 43, 548-569.

Shipley, Thomas E. Jr. 1987. Opponent-Process Theory. In H.T. Blane & K.E. Leonard, (eds.), Psychological Theories of Drinking and Alcoholism. New York: Guilford Press, 346-387.

Shipley, Thomas E. Jr. 1988. Opponent-Process, Stress, and Attributions: Some Implications for Shamanism and the Initiation of Healing Relationships. Psychotherapy 25: 593-603

Shipley, Thomas; Shandler, Irving; and Michael Penn. 1989. Treatment and Research with Homeless Alcoholics. Contemporary Drug Problems Fall

Sorge, Rod. 1991. Harm Reduction: A New Approach to Drug Services. Health/PAC Bulletin Winter

Springer, Edith. September 1996. The Spectrum of Harm Reduction. New York Peer Aids Education Coalition.

Stark, M.J. 1992. Dropping Out of Substance Abuse Treatment: A Clinically Oriented Review. Clinical Psychology Review, 12, 93-116.

Thomas, Lisa; Kelly, Mike; and Cousineau, Michael. 1990. Alcoholism and Substance Abuse. In P. Brickner, L.K. Scharer, B. A. Conanan, M. Savarese, & B. C. Scanlon, (eds.) Under the Safety Net: the Health and Social Welfare of the Homeless. NY: Norton and Co.

Tims, Frank, Fletcher, Bennett & Robert Hubbard. 1991. Treatment Outcomes for Drug Abuse Clients. In Roy Pickens, Carl Leukfeld, & Charles Schuster, (eds.) Improving Drug Abuse Treatment. Alcohol, Drug Abuse and Mental Health Administration, Research Monograph 106. US DHHS Public Health Service. U.S. GPO.

APPENDIX 1: THE SPECTRUM OF HARM REDUCTION BY EDITH SPRINGER

HIV-Related Interventions
* syringe exchange
* bleaching injection equipment
* promotion of safer sex
  referrals to HIV antibody testing
* referrals to HIV-related medical care
* referrals to/provision of HIV psychosocial care and case management

Ancillary Interventions
* referrals to/provision of wide spectrum of care
* entitlements
* housing
* alternative and holistic therapies (e.g., massage, acupuncture, nutritional counseling)
* psychotherapy
* support groups
* healing centers (e.g., yoga, meditation, wellness work)

More Compassionate Drug Treatment Abstinence-Oriented Programs

Use of harm reduction strategies to attain abstinence for those who desire it; goal of abstinence must be freely chosen by consumer; moderation goals accepted; consumer treated with dignity and respect
* Prochaska-DiClemente's stages of change
* motivational interviewing
* acupuncture detox
* slow reduction course detox
* medicate withdrawal symptoms during detox
* consumer sets time frame for change: client centered care

Chemotherapeutic Options:
Non-controlling; consumer has autonomy
* methadone maintenance
* LAAM
* antabuse or naltrexone freely chosen
* anti-depressants for cocaine and crack users

Additional Improved Drug Treatment Options
* drug substitution therapies (e.g. buprenorphine)
*medical maintenance on drug of choice (e.g. heroin maintenance)
*methadone prescribed by primary care physicians
* federal and state methadone regulations changed to eliminate over control, infantilization, loss of freedom, and stigma, and to allow consumers to be normalized in society
* new combinations of interventions (e.g., residential methadone maintenance, inpatient acupuncture detox)

Drug Use Management Interventions
For those who want to continue using drugs
* research into experimental treatments (e.g., ibogaine)
* teach safer drug use (e.g., proper injection techniques);
* abscess management; vein care;
* advice regarding drug combinations;
* changing route of administration;
* safer cropping;
* substitution of less harmful drugs; (overdose prevention and management)
* encourage more responsible drug use (e.g., more control over when, how often, where, how and with whom one uses; taking care of business first: maintaining entitlements and housing, keep medical appointments, respecting the rules of the agencies regarding drug use on the premises, buy the pampers first!)
* changing drug use (e.g., controlling dosage, cutting down)
* make related behaviors safer (e.g., prostitution; less violence)

Advocating for Changes in Drug Policy
* treatment versus incarceration; more and better drug courts
* changes in drug paraphernalia laws
* reduction in penalties for drug related offenses
* rehabilitation and vocational training in prison

Edith Springer is a harm reduction trainer and Clinical Director of the New York Peer AIDS Education Coalition (NYPAEC)

APPENDIX 2: MQOL-HIV Questions Separated by Domain

Time Frame of Questions: in the past two weeks...
Answered on a scale of:
1=never, 2=seldom, 3=sometimes, 4=about as often as not, 5=frequently, 6=very often, 7=always, 8=not applicable

Mental Health
1. You felt depressed
2. You felt anxious
3. You felt needed
4. You worried about things

Physical Health:
5. You had health problems
6. You were too tired to the things you wanted to do
7. You were bothered by nausea
8. You were bothered by sensations

Physical Functioning:
9. You were able to do things around the house
10. You were able to get from place to place, such as shopping and to the doctor
11. You were able to climb several flights of stairs without help
12 you could perform strenuous sports like running or weight lifting

Social Functioning
13. You felt isolated
14. You have withdrawn form socializing
15. You lacked energy to socialize with friends
16. You spent quality time with friends

Social Support
17. You have received enough emotional support from people close to you
18. You had someone who could help you in an emergency
19. You had someone you could talk to about problems
20. You had someone who could give you useful advice

Cognitive Functioning
21. You were bothered by trouble remembering things
22. You were bothered by forgetting what you started to do
23. You have found that your mind wanders more than usual
24. You were bothered by a short attention span

Financial Status
25. You had to put off paying regular living expenses
26. You have not had enough money to pay for medication
27. You have not had enough money to pay for recreational activities
28. You were concerned about your financial future

Partner Intimacy
29. You felt satisfied with the activities you do with your spouse or your partner
30. You felt satisfied with the amount of affection your spouse or partner expressed toward you
31. You were able to confide in your spouse or partner
32. You felt mistrust for your spouse or partner

Sexual Functioning
33. You felt satisfied with your sexual activity
34. You have wanted sex more often than you have had sex
35. You felt afraid of infecting someone through sexual contact
36. You felt afraid of sexual rejection

Medical Care
37. You wanted more information from your health care providers
38. You wanted more support from your doctors and other health providers
39. You doubted that you health providers are doing all they can for your health
40. You were able to get the medical care you needed

Avis, Nancy & Smith, Kevin. 1994. MultiDimensional Quality of Life Questionnaire for Persons with HIV/AIDS. New England Research Institutes: Watertown, MA.