The Collaborative Care Management Program

East Boston Neighborhood Health Center

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East Boston Neighborhood Health Center
East Boston, Massachusetts

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Project Description

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Location and Context

Location. The Collaborative Care Management Program is located at the East Boston Neighborhood Health Center in Boston, Massachusetts. Boston, the state capital and largest city in Massachusetts, has a population of approximately 600,000, about 10 percent of the total state population.

The East Boston Neighborhood Health Center was established in 1975 as a community-owned and operated health center. It serves the communities of Chelsea, Revere, East Boston and Winthrop, low income and working class communities that are geographically isolated from the city of Boston proper by congested tunnels and bridges.

The EBNHC service area includes immigrant communities populated initially by Italians, as well as Central Americans, Brazilians and Asians who began arriving in the area in the 1980s. Many residents are undocumented and thus uninsured, while others have private health insurance, Medicaid or Medicare.

The health center provides a full complement of primary care services, including adult medicine, pediatrics, obstetrics and gynecology; a full spectrum of specialty care; mental health services; a 24-hour urgent care facility; and laboratory, radiology, and other services. EBNHC is affiliated with Massachusetts General Hospital and Boston Medical Center, and provides more than 300,000 visits annually. It is the largest community health center in New England.

EBNHC has been in the forefront of developing community-based services for both the general population and special needs populations, such as frail elders, in its service area. In 1992, the health center decided to extend this experience to develop and implement comprehensive programs for other complex patient populations, including people with HIV and AIDS. In 1994, the East Boston Neighborhood Health Center received a grant from HRSA under the SPNS program to develop an integrated model of care for individuals with HIV/AIDS. Project SHINE (Support, Healthcare, Intervention and Education) was designed as a community-based program that used a multidisciplinary team approach to caring for people with HIV/AIDS. The goal of Project SHINE was to organize and coordinate medical care for the health center's HIV positive clients, and has proven to be a successful model of care for this population at the health center. It has since become a permanent department at the Health Center after the demonstration ended in 1999.

CCMP was developed to complement Project SHINE, with a goal of extensive integration and coordination between the two programs. While Project SHINE focused upon patients' medical needs, CCMP was intended to address the mental health, substance abuse, and care management needs of HIV positive health center clients. Project SHINE was expected to serve as CCMP's primary referral source of HIV positive individuals who were additionally diagnosed with severe mental health and/or substance abuse disorders.

Population Served

The four communities served by the East Boston Neighborhood Health Center range in racial and ethnic diversity.[*] Winthrop is over 94 percent white. The population of Revere is 79 percent white, 9 percent of Hispanic/Latino origin, and 5 percent Asian/Pacific Islander. Meanwhile, Chelsea's population is 38 percent white, with 48 percent of Hispanic/Latino origin, 7 percent black, and 5 percent Asian/Pacific Islander, while East Boston's population is 50 percent white, 39 percent of Hispanic origin, 3 percent black and 4 percent Asian/Pacific Islander.

The health center's catchment area is poor compared to the rest of the state, and three of the four communities are substantially poorer, as measured by receipt of public assistance and percent of individuals living in poverty. As a result of the high poverty rates, a substantial portion of the overall population receives some form of public assistance. A 1998 report on the health center's catchment area stated that 25% of Chelsea's population sought assistance from public funds. In East Boston, 15% of residents received public assistance, as did 12% of Revere residents. However, less than 4% of Winthrop residents relied upon public assistance.[†]

Additionally, substance abuse rates are high in these communities, compared to the rest of Massachusetts. For example, the rate of substance abuse related deaths in Chelsea is 26 percent of all deaths, compared to the state rate of 15 percent.[‡]

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[*] All demographic statistics cited for these communities come from the 2000 United States Census, unless otherwise noted.

[†] From *Executive Summary for East Boston, Chelsea, Revere and Winthrop*, Beacon Health Strategies, 1998.

[‡] From *Executive Summary for the Municipality of Chelsea*, Beacon Health Strategies, 1998.

The CCMP program enrolled 41 individuals: 31 who were HIV positive with co-morbid mental health and/or substance abuse disorders, as well as 10 with serious mental health and/or substance abuse disorders who were at risk of contracting HIV, and who served as the comparison group for the evaluation. The most common DSM-IV Axis I diagnoses at intake were major depression, polysubstance abuse, and alcohol abuse. Nearly one third of clients also presented with an Axis II personality disorder.

The CCMP clientele was poor, with an average yearly income of $8,786 at intake. Nearly half were precariously housed (doubled up or living in a shelter) when they started the program. Three quarters of the population have experienced homelessness at some time in their lives; additionally, over two thirds have been arrested in the past, and nearly half have been incarcerated.

Intervention Goals and Needs Addressed

The mission of the Collaborative Care Management Program was to provide intensive care management, as well as coordinated and linked medical, mental health, substance abuse and support services to HIV positive EBNHC primary care patients with the greatest needs.

The goals of the program included:

- Engaging hard-to-serve individuals in treatment through the introduction of a master's level care manager, experienced in dual diagnosis (mental health and substance abuse) as well as in HIV/AIDS;
- Increasing integration of primary care, mental health and substance abuse treatment;
- Increasing cost effectiveness and improving outcomes through changing patterns of care;
- Developing critical linkages with community mental health and substance abuse agencies;
- Providing culturally competent care to a diverse client population by meeting staff training needs and developing specialized linkages with agencies that could provide culturally competent care; and
- Establishing program replicability and sustainability.

Approximately 80% of EBNHC's HIV infected patients suffer from complex, persistent mental health and substance abuse disorders. Their need for services exceeds those that a primary care organization can reasonably provide, and frequently requires referrals to outside agencies for substance abuse treatment, detoxification, and/or psychiatric inpatient services. Prior to the development of CCMP, coordinated, comprehensive care for multiply diagnosed HIV positive individuals was compromised by poor communication and inadequate linkage between primary care and other services, lack of immediate access to critically needed services, and the varying degrees of quality and capacity to deliver culturally and linguistically sensitive services among affiliating agencies. Thus, the focus of the program was to improve access to and quality of substance abuse and mental health services for EBNHC's high-risk patients by securing a more reliable service bridge between primary care and these critically needed services.

The program addressed important structural needs as well in order to reduce fragmentation of care. Despite providing a wide range of services as a community health center, EBNHC does not directly provide the full range of medical, mental health and substance abuse services, such as methadone maintenance, inpatient treatment, day treatment, and detoxification, that are often required by HIV infected patients with mental health and substance abuse disorders. To adequately serve this population, referrals are made to outside agencies for a range of substance abuse services, inpatient treatment, detoxification, and day treatment. Before CCMP, there were no formal relationships between EBNHC and outside agencies that received referrals from health center staff.

Evaluation Methods and Results

As a research and demonstration project, it was mandatory that CCMP be evaluated. In order to assess the effectiveness of CCMP, both quantitative and qualitative analytic methods were used. Outcome measures for the quantitative analysis included measures of life functioning, measures of health status and functioning, service changes in psychiatric functioning, cost and utilization, consumer satisfaction, and satisfaction of both EBNHC providers and linkage agency providers with the program.

Outcome Measures

Quantitative outcomes were measured in several ways. Cost and utilization was measured through chart review. Client records were reviewed to determine utilization of an extensive range of medical, mental health, substance abuse and support services for 12 months prior to program enrollment, and through each client's entire enrollment period. Data was collected on a monthly basis. Several medical indicators were obtained from chart review, including CD4 counts and viral loads, on a biannual basis. Psychiatric functioning was determined from changes in DSM-IV diagnosis and GAF scores, reassessed biannually by the care manager. This data was obtained through chart review; outcomes were compared from entry into the program through the entire enrollment period. Finally, the last quantitative outcome measure was provider satisfaction. Three rounds of interagency linkage data were collected, using a written survey, over the life of the grant; changes in satisfaction of both EBNHC providers and linkage agency providers with the program were analyzed.

Qualitative outcomes were measured in three ways. First, a process evaluation was produced in the form of a program timeline and chronology. This includes much of what happened to the program from conceptualization to inception to implementation. Second, both clinical and evaluation staff perceptions of outcomes and experiences were collected through a semi-structured interview tool that addressed both their experience and their perception of enrollees' experiences and outcomes. Common themes were identified using grounded theory as the analytic model. Finally, CCMP attempted to embrace certain social work principles by integrating micro and macro practice and encompassing a broad, generalist perspective. This process was described through a qualitative and descriptive analysis of the role of the care manager.

Findings

Below, some of the findings are presented. A few caveats are important to mention here. Although CCMP was a five-year demonstration, program development and implementation took a great deal of time, and the initial clients were enrolled 15 months after the grant was awarded (second quarter of year 2). Clients were enrolled on a rolling basis, and some clients did not enroll until later in year 2, during year 3, or early in year 4. Few clients were in the program for more than two years. Therefore, data are only presented at intake, 12 months after each client's enrollment (year 1), and 24 months after enrollment (year 2). Additionally, because of low numbers, EBNHC decided, with HRSA's approval, not to enroll any new clients after the end of year 4, as the program was ending in 12 months. However, current CCMP clients continue to receive the CCMP model of care management services.

In addition, this population was extremely difficult to retain in care for extended periods, particularly in an office-based program. Clients were frequently lost to follow-up, would reappear after extended absences, or miss scheduled appointments. The results below are presented with these limitations.

CCMP served two groups of clients: clients who were HIV positive (n=31), as well as a smaller group of clients who were considered "HIV at risk" (n=10).

All statistics presented below were collected at intake, unless otherwise noted.

Demographics

Gender

	HIV Positive (n=31)	**HIV At-Risk (n=10)**	**Total (n=41)**
Male	17 (55%)	6 (50%)	23 (56%)
Female	14 (45%)	4 (40%)	18 (44%)

Race/Ethnicity

	HIV Positive (n=31)	**HIV At-Risk (n=10)**	**Total (n=41)**
Black (including African-American Black and Caribbean Black)	6 (19%)	0 (0%)	6 (15%)
Latino/a (including Puerto Rican and Other Caribbean)	5 (16%)	0(0%)	5 (12%)
White	20 (65%)	10 (100%)	30 (73%)

Sexual Orientation

	HIV Positive (n=31)	HIV At-Risk (n=10)	Total (n=41)
LGBT	11 (35%)	1 (10%)	12 (29%)
Heterosexual	20 (65%)	9 (90%)	29 (71%)

Median Age

	HIV Positive (n=31)	HIV At-Risk (n=10)	Total (n=41)
Median Age	35.5	41.5	36.0

The following statistics are for the entire study group (n=41).

Housing Status

- 14 (33%) doubled up with others
- 11 (27%) owned own house or apartment
- 10 (25%) lived in AIDS or supported housing
- 6 (15%) lived in a shelter, on the street, or in jail
- 29 (77%) of clients had been homeless in the past
- 19 (46%) had been homeless within 6 months of intake

Legal System Involvement

- 29 (70%) of clients have been arrested in the past
- 19 (46%) have been incarcerated in the past

Education

- 55% of clients received less than grade 12 education
- Mean level of education was 9.6 years

Income

- Mean yearly income of CCMP clients was $8,786
- 22 (54%) clients received welfare benefits (including SSI, TANF, food stamps and general relief funds)
- 9 (22%) received SSDI benefits

Insurance Status

- 29 (71%) had Medicaid
- 9 (22%) had Medicare
- 1 person had private insurance
- 2 people had no insurance

These data indicate a population that is poor, undereducated, and largely living in temporary housing. Moreover, few have significant work histories as seen by the low percentage of

individuals receiving SSDI, rather than SSI or other welfare benefits. This is true for both the HIV positive and the HIV at-risk groups.

HIV Status, CD4 Counts, and Viral Load

CD4 count and viral load data were collected for clients in the HIV positive group, as displayed in the tables below.

CD4 Means Over Time

	Baseline (n=30)	**Year 1 (n=19)**	**Year 2 (n=8)**
CD4	398.9 (SD: 357.3)	568.4 (SD: 478.3)	431.3 (SD: 323.1)

Viral Load Means Over Time

	Baseline (n=27)	**Year 1 (n=17)**	**Year 2 (n=7)**
Viral Load	794,000 (SD: 137,383.7)	34,394.8 (SD: 91,639.5)	113,694.4 (SD: 291,693.2)

It is difficult to use these clinical indicators as indicators of medical improvement. Due to their mental health, substance abuse and social problems, these clients were difficult to track down and frequently did not engage fully in the CCMP program for lengthy periods. Therefore, the client numbers are too small, particularly after the 24-month enrollment period, and the standard deviations too large, to make any definitive statements. However, it does appear that after one year, when clients are likely to be most easy to reach, there was a trend toward improvement.

Mental Health

The most frequent DSM-IV Axis I mental health diagnoses for CCMP clients were major depression, polysubstance-related disorders, and alcohol related disorders; this pattern was similar for both HIV positive and HIV at-risk clients. Most individuals had multiple Axis I diagnoses. In addition, 13 clients (32%) presented with Axis II diagnoses at intake, most frequently with borderline personality disorder as well as other assorted personality disorders. One client had mild mental retardation. Twenty-nine percent of the 31 HIV positive clients were diagnosed with an Axis II disorder, while 40% of HIV at-risk clients received an Axis II diagnosis.

At intake, clients presented with a host of issues that were documented as Axis IV diagnoses (psychosocial stressors). These included:

Psychosocial stressor	HIV Positive (n=31)	HIV At-Risk (n=10)	Total
Problems with primary support system	13 (42%)[§]	3 (30%)	16 (39%)
Housing problems	13 (42%)	2 (20%)	15 (37%)
Problems with social environment	8 (26%)	3 (30%)	11 (27%)
Legal problems	5 (16%)	0 (0%)	5 (12%)
Economic problems	5 (16%)	1 (10%)	6 (15%)
Problems with access to health care	2 (6%)	1 (10%)	3 (7%)

CCMP enrollees faced multiple challenges, most often issues with housing and problems with the primary support system. These difficulties generally declined in number to some degree as clients received care management through CCMP. However, housing problems and problems with primary support system remained fairly common.

Finally, Axis V Global Assessment of Functioning scores were assigned to measure overall functioning. The table below documents the change in the mean GAF score over time.

Mean GAF Scores Over Time

Year	HIV Positive	HIV At-Risk	Total N
Baseline	45.8 (n=28)[**]	46.7 (n=9)	46.0 (n=37)
Year 1	47.6 (n=19)	47.8 (n=4)	47.7 (n=23)
Year 2	51.3 (n=6)	44.3 (n=3)	49.0 (n=9)

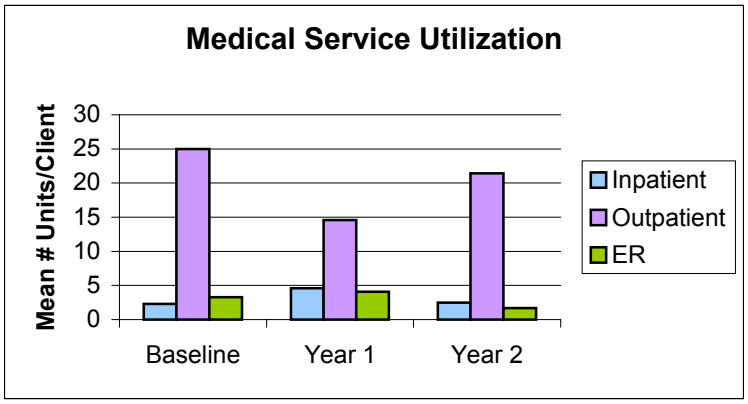
GAF scores showed some minimal improvement over time; however, they indicate a fairly low level of functioning for CCMP clients overall. There is no statistically significant difference between the HIV positive and the HIV at-risk populations with regard to this difference.

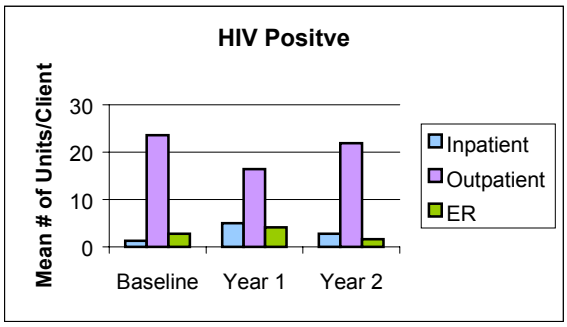
[§] Percentages add up to over 100% because one may be diagnosed with multiple psychosocial stressors.

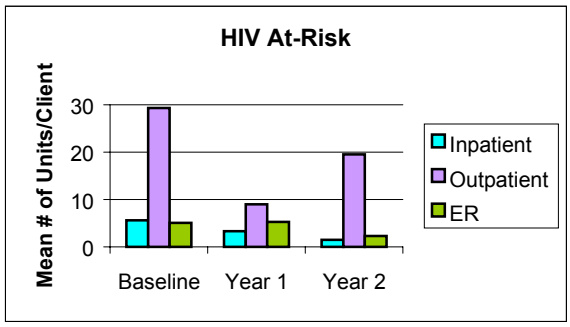
[**] The *n* is less than the total *n* for each group because it was difficult for the clinicians to see some clients enough to assign GAF scores to them.

Service Utilization

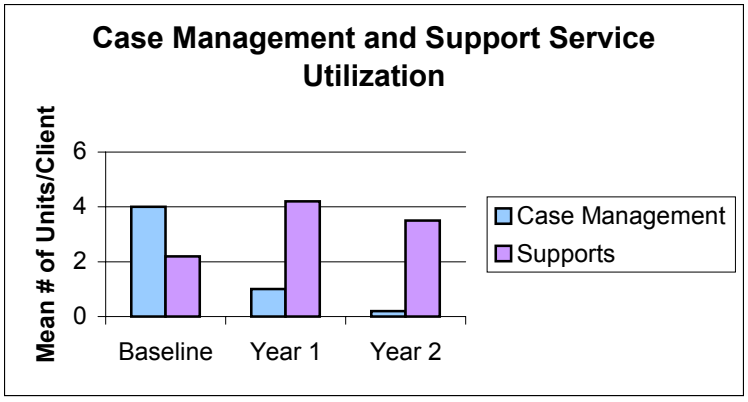
Service utilization data was collected for each client for 12 months prior to CCMP enrollment, as well as monthly for the duration of the client's stay in the program. The graphs below illustrate selected patterns of service utilization.

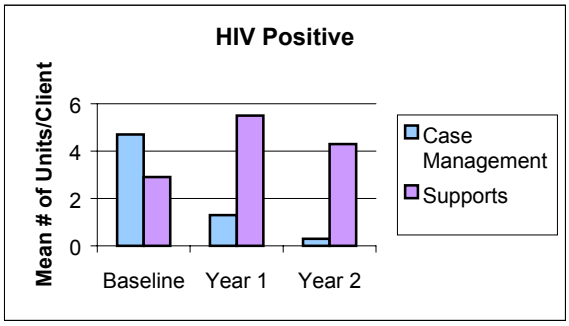


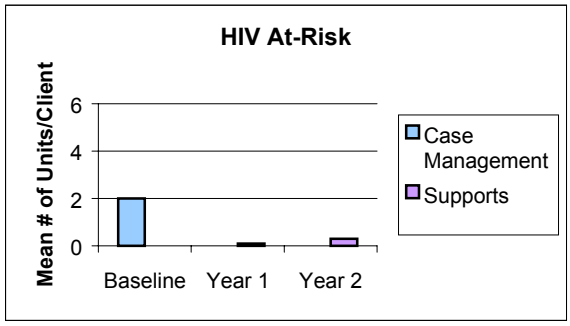




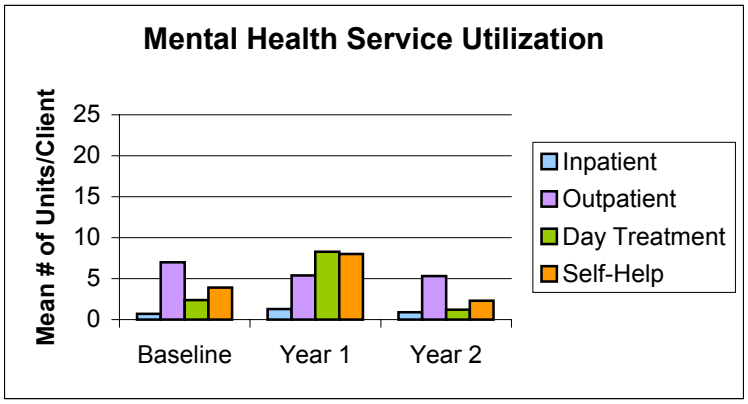
Although there was no increase in outpatient care over time, clients did continue to access this service. Importantly, after increases in the first year of program participation, clients experienced decreases in both inpatient care and emergency room treatment over the life of the program.

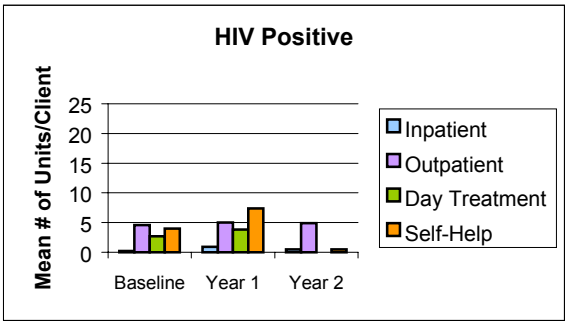


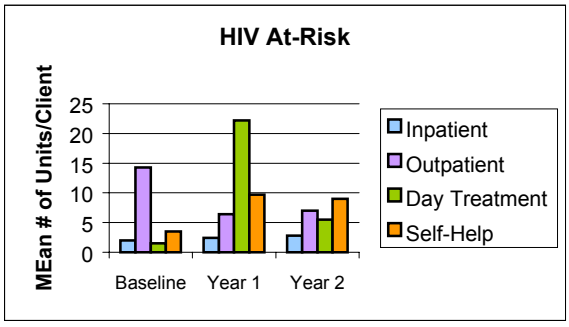




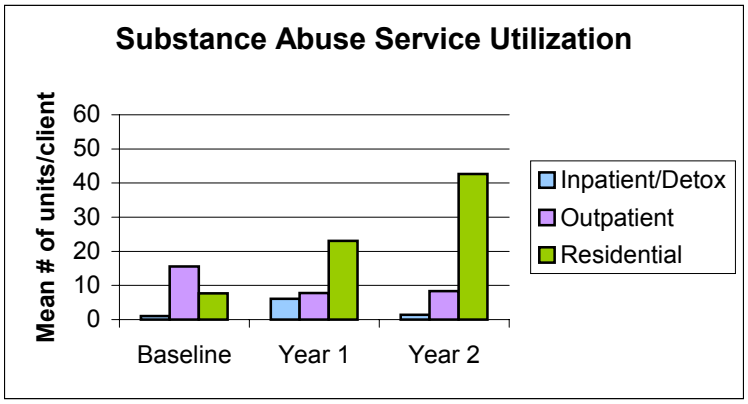
Because clients received care management through CCMP, clients used outside case management less often after they enrolled in the program. Care management also gave clients increased access to supports. HIV positive clients received many more support services; however, clients in the at-risk group had received no supports in the year prior to enrollment, so any increase after baseline was an improvement.

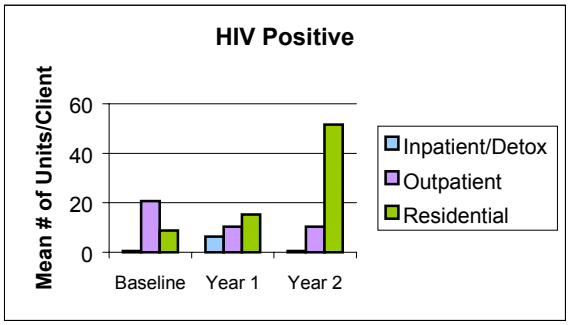


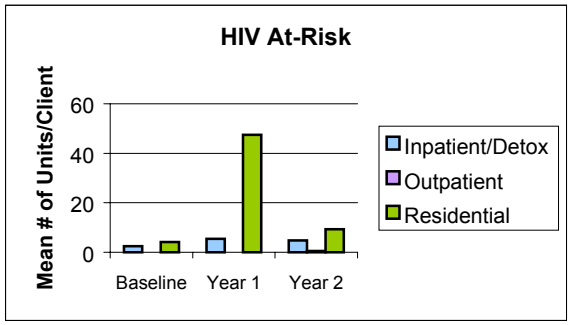




Generally, clients received more mental health care in the first year of the program; usage declined during the second year of enrollment. The at-risk group consistently used more services than the HIV positive group, indicating a higher level of mental health acuity, and thus their need for this program for the purpose of managing the mental health needs and changing the patterns of care, despite their HIV-negative status.







Overall, residential service utilization climbed dramatically over time, while inpatient treatment peaked in the first year and outpatient treatment declined. This pattern is reproduced in the HIV positive group; however, the HIV at-risk group showed a different pattern: almost no treatment received except residential treatment during the first year of the intervention.

Service Cost

Costs were assigned to services received by CCMP clients. The table below shows the changes in total cost per client over time.

Service Cost Means

Year	HIV Positive	HIV At-Risk	Total
Baseline	$7,558.74 (n=31)	$12,590.65 (n=10)	$8,786.04 (n=41)
Year 1	$10,147.25 (n=31)	$13,258.72 (n=10)	$10,906.14 (n=41)
Year 2	$7,394.91 (n=15)	$9,391.37 (n=4)	$7,812.22 (n=19)

*These costs do not include the CCMP case management/evaluation cost per client; the mean cost for CCMP case management Year 1 was $1,690 per client, while the mean cost for Year 2 was $1,696 per client.

Overall cost peaked in the first year of clients' enrollment, and then decreased to an all-time low by the second year. However, if the cost of care management is included, the cost of year two remains higher than baseline. This data indicates that the program did not lead to decreases in cost. However, the patterns of service use did change, with clients accessing more care

management, outpatient services and stabilization services over time such as substance abuse residential programs, and requiring less inpatient and emergency care. Patterns such as these are crucial, and reflect the importance of the CCMP program in potentially enhancing overall quality of life.

Linkage Outcomes/Provider Satisfaction

As discussed earlier, there was a need for increased systemic collaboration both within the health center (i.e., between departments and staff) as well as between the health center and outside agencies. This was measured through the annual linkage surveys.

Upon examining results from the three rounds of linkage surveys, it would appear that, superficially, not much as changed since the beginning of the intervention. Overall level of knowledge about agencies has not risen (59% of providers had moderate or "a lot" of knowledge about linkage agencies at Round 1, and 54% had the same level of knowledge at Round 3), and overall satisfaction with services provided by outside agencies rose by only two percentage points from 78% to 80% by the second year of enrollment. However, many more formal linkages exist now than at the beginning of the program, including formal agreements with inpatient mental health services, inpatient detoxification programs, and residential treatment programs. This is no small achievement, because it has enabled the CCMP clients to access much-needed care that was difficult for them access prior to being enrolled in the program.

Implications, Observations and Insights

The Collaborative Care Management Program did not grow very large due to a variety of reasons. However, it does appear that from the CCMP experience, appropriate care management can change patterns of care from a reliance on inpatient and acute treatment to outpatient care. Some of the very complex clients enrolled in the project benefited from an intense and comprehensive treatment plan and have had significant improvement in their quality of life. Care managers have reported increased sobriety, better medical adherence, and increases in CD4 counts.

It is a great challenge to provide comprehensive services in a system of care that fosters fragmentation more than it facilitates integration. Working with a challenging population such as people with addictive behavior and severe mental illness in a fragmented system of care is a daily struggle. There is fragmentation in the delivery of services for people with multiple problems, and agencies have non-inclusive criteria for clients with multiple diagnoses. There are also attitudinal barriers, such as lack of provider awareness of the nature of co-occurring disorders, consumers' distrust of providers, and the dearth of culturally appropriate programs.
The CCMP model of care management is necessary for a range of complex clients, not only those who are HIV positive. Those in the HIV at risk group benefited from changing patterns of care and connections to mental health and substance abuse services. Without this type of intensive care management, very complicated clients can fall through the cracks of the current system, especially if they are substance abusers. One of the major strengths of the program was

that the Care Managers followed the clients throughout the system of care, and that there were no funding barriers due to the grant funding.

Although it was ambitious, it is unclear if the program expected too much of itself. As one of the care managers stated, "The primary problem with the project is in many ways what makes it most challenging– its complexity. The goals of the project were overly ambitious and there were too many components of the project for the resources allocated. An entire agency could be designed to do what a small group of people thought they could accomplish (client care, research, cultural competence, linkages, etc.)."

The evaluation and the clinical agendas sometimes conflicted, but in the end, the model was a wonderful example of participatory evaluation and mutual respect. The evaluation team and the clinical team truly became one. However, this was not accomplished without pain. For future programs that are clinical in nature and target extremely high-risk populations, it will be important to limit data collection as much as possible. It was challenging to try to meet the needs of both a local and a multi-site evaluation, and not lose the clinical, client-centered focus. Funders of research and demonstration projects should take this into account, formulate appropriate research questions, and target the research issues with survey tools that are as brief and concise as possible.

Both the clinical team and the evaluation team learned a great deal from this process. The evaluation team was able to truly put the concepts of participatory evaluation into practice. For the clinical team, the opportunity to work with small numbers of very complex individuals was important for professional development: "A large superstructure was created to hold only a handful of clients. On one level this was good for me because I received a tremendous amount of supervision for a few clients. This allowed me the luxury to delve in-depth and explore the motivations of the clients, thus illuminating my comprehension of Axis II disorders, substance abuse treatment, and HIV care. Ultimately, I know the experience made me a better and more sophisticated clinician."

In sum, the staff believe that …

"[T]he greatest accomplishment of the program would not be evident in the data, but I believe CCMP improved the care of the HIV patients and made this a better health center. Before CCMP, Project Shine and the mental health department lived in opposite worlds that rarely interacted. There was a suspiciousness felt between the two departments that generated a level of mistrust. We were a fragmented health center in that respect. CCMP bridged that gap and created an integrated model of care that addressed the medical and mental health needs of the Project SHINE clients. We instituted new policies and procedures to ensure that these changes would remain intact beyond the life of the project and this has proven to be true. The nurses and the case managers at Project SHINE rely on the mental health clinicians to handle and consult around mental health issues, it is a seamless integration at this point which benefits both staff and the clients…"

and,

"As John Lennon once said, 'Life is what happens while you are making other plans.' This project was a success because it altered the structure and management of the health center and created a more cohesive and comprehensive level of care for the clients. We realized that what we saw as the obstacle to client care in the community, i.e., fragmentation of service, the need for linkages and the coordination of care, was occurring internally as much as it was with outside providers. This was a tremendous insight and it evolved out of the problems and frustrations of CCMP. Without the project, this positive change may not have occurred and it exemplifies the way in which grand expectations may not be met but the effort and the endeavor to improve oneself or one's environment can result in unexpected outcomes."

Appendix: “A Games of Snakes and Ladders” poster

A Game of Snakes & Ladders*:

(*Referring, of course, to the classic game upon which Chutes and Ladders™ is based.)

The Journey of the Collaborative Care Management Program East Boston Neighborhood Health Center

1997-2001

The biggest disappointment was the **lack of patients**. I never carried a caseload that approached the amount of clients I was supposed to follow. This felt frustrating and ultimately a kind of despondency and grief began to take over the project, killing the initial excitement and hope that the expectations could be met...
A large superstructure was created to hold only a handful of clients.

In terms of my own professional development, I felt I had been handed either a **potential diamond in the rough** to buff out or a ***white elephant.***

In getting to the point of mutual respect [between clinical and evaluation staff], there was a ***lot of pain***. That was a disappointment to me. I know that I underestimated or was not aware of some of the feeling about the evaluation aspect of this. I think I have learned a great deal about how to approach these types of evaluations from this process, and how important it is to be involved early on and to use the ***participatory evaluation model.***

East Boston's bankruptcy had a huge impact on CCMP. When the grant was written, the health center was expected to grow and expand. After Chapter 11, EBNHC scaled back and looked within. We did not get enough referrals to keep the program running and the linkage agreements could not really develop because they weren't being used.

I know for some clients CCMP was the support that allowed them to change their lives, stay clean and sober, get adequate housing and see their viral load drop to undetectable. If CCMP helped to make this real for only a handful of clients then this was a success ***because it literally saved lives.***

CCMP was one of the only programs that I know of that worked with [hard core drug addicts] in a comprehensive way. One of the major strengths of the program was that the Care Managers followed the clients throughout the system of care. There are so many cases in which I still see the need for this level of intervention and there don't seem to be any funders that pay for this type of service.

The greatest accomplishment of the program would not be evident in the data but I believe CCMP improved the care of the HIV patients and made this **a better health center.**

The CCMP team became better respected and its expertise... especially in the area of substance abuse, the impact of personality disorders, etc, was finally appreciated and acknowledged.

I am extremely proud of the hard work we put in... I am also proud of the fact that we really **became a team** in every way, and came to really appreciate each other both as people and colleagues.

The quotes featured on this poster are results from a qualitative survey of CCMP clinical and evaluation staff, August, 2001.

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