Needs of Ex-Offenders with HIV Released into the Community

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Abstract

Objectives. This research assessed the service needs of incarcerated individuals living with HIV who received intensive case management services from the Massachusetts Transitional Intervention Project (TIP) to support their reintegration into the community.

Methods. This was a multi-method needs assessment that used TIP programmatic data on 884 clients with 1,265 cases, and focus groups and interviews with 28 TIP clients, 12 TIP case managers in the community, seven HIV coordinators in jails, and five infectious disease coordinators in prisons.

Results. Most clients need help procuring health care, housing and substance abuse treatment. Most clients have a history of substance abuse, but many initially declined substance abuse treatment services.

Conclusions. Inmates living with HIV have multiple needs to ensure successful transition to the community.

Background

Between 1980 and 2000, the number of inmates in jails and prisons in the United States burgeoned from under 500,000 to more than 2 million. Massachusetts currently holds more than 20,000 inmates. Almost all (97%) of these people will eventually be released to the community.[3]

Persons incarcerated in correctional systems comprise approximately 0.7% of the U.S. population but have a disproportionately greater burden of infections of public health importance, including hepatitis, human immunodeficiency virus [HIV], sexually transmitted diseases, and tuberculosis.[10] The prevalence of AIDS among inmates is five times higher than among the general U.S. population.[10] In 1996, 17% of persons living with AIDS, and 13-19% of those with HIV, passed through a correctional facility.[11]

Inmates exhibit behaviors that reduce the likelihood they will follow good public health practices when they return to the community. The Office of National Drug Control Policy reports that 50-70% of the offender population has a diagnosed substance abuse disorder.[6] Various mental health disorders are also prevalent. In prisons, these include major depression (13-19%), long-term depression (8-14%), anxiety disorder (22-30%) and schizophrenia (2-4%).[13] Rates for these disorders among jail inmates are lower, but still comparable.

In Massachusetts, the estimated prevalence of HIV in 2001, at 3.0% (2.8% of male prisoners and 5.7% of female prisoners), was 50% higher than the national average, and the prevalence of confirmed AIDS, at 1.2%, was more than twice the national average. Fifty-nine percent of men and 68% of women entering the Massachusetts prison system reported past injection or inhalation of drugs.[7] Twenty-seven percent of male inmates and 44% of female inmates are infected with hepatitis C.[8]

This research sought to answer determine the service needs of individuals living with HIV who are released from Massachusetts correctional institutions. The individuals are clients of the Transitional Intervention Project (TIP), a statewide public-private partnership that provides intensive case management services to support the successful reintegration of incarcerated individuals living with HIV back into the community. TIP is administered by the HIV/AIDS Bureau (HAB) of the Massachusetts Department of Public Health (MDPH). During the time period reported here, it was funded as part of the national Corrections Demonstration Project by the HAB, the U.S. Centers for Disease Control and Prevention (CDC) and the Health Resources

and Services Administration (HRSA). The HAB hired *Capacities*, a private research firm, to conduct this needs assessment of TIP clients.

Method

This was a multi-method study, using both quantitative data – i.e., programmatic data collected by TIP case managers – and qualitative data – i.e., focus groups and interviews with TIP clients, TIP case managers and correctional staff. The protocol was reviewed and approved by the MDPH Institutional Review Board, and informed consent was obtained from all participants in the interviews and focus groups.

Sample and Data Collection Procedures

Programmatic data

Programmatic data from MDPH included three levels of data: client level, case level, and event level. Clients who were re-incarcerated would begin a new case. For each case, at intake, TIP case managers recorded standard demographic information about the client, such as age, ethnicity, gender, race and marital status.

For each case, at intake, TIP case managers also recorded case information, which included the date the case was opened, case status, release date, date case was closed and the TIP service provider. A summary of short-term and long-term needs was also recorded, where the types of needs were categorized as: Basic needs (food, clothing), Housing, Medical care, Mental health treatment, Substance abuse treatment, Transportation, Other (employment, entitlements, insurance, legal, risk reduction, family services).

Detailed assessments at intake were available for a sub-sample of cases. Assessments completed before mid-2002 used a questionnaire that was designed as an aid for the case managers as they developed their service plans. After mid-2002 assessments were entered onto a scannable form, and completion became mandatory.

The assessment determined whether or not the individual had received treatment for HIV (not limited to medication), mental health, or substance abuse, whether they had a relationship with a provider of health care, mental health care or substance abuse treatment in the community and, if so, whether they plan to return to those providers or, if not, whether they need a referral. It also assessed their needs for assistance to secure HIV care in the community, their plans for a supply of medication on discharge, and whether they need "bridge services" (i.e., interim

services until a permanent treatment provider can be secured) for mental health or substance abuse. It identified other medical conditions, such as Hepatitis C and developmental disability. Finally, it ascertained prior housing, housing preferences after release, realistic options, and offenses (violent crime, arson, sex offense) that usually pose obstacles to housing choices.

As the case progressed, case managers also recorded utilization ("event") data by case for each service and monitoring activity. The broadest category of service event was case management, which included activities involving advocacy, building trust, counseling, escorting/ transporting, follow-up, service planning, and generic case management. Other service events were setting up appointments and procurement of services (e.g., medical treatment, mental health treatment, substance abuse treatment, medications, and non-medical assistance). Service events also identified which needs were being addressed, using the same categories as those described for cases, above.

We constructed dichotomous need variables in five areas by counting affirmative responses to the items listed below from the case intake, the detailed needs assessment, and subsequent needs assessment events (Although the categories were comprised of different numbers of items, this difference was not deemed problematic because scores were not compared to each other):

- Medical care: needs medical care or HIV care, needs referral to physician, needs someone to accompany to doctor appointments, needs reminding/ help with forms/translation at doctor appointments, has no insurance.

- Mental health care: needs mental health treatment, has a history of mental illness or mental health treatment, needs referral or bridge services for mental health treatment

- Substance abuse: needs substance abuse treatment, has a history of substance abuse or substance abuse treatment, needs referral or bridge services for substance abuse treatment

- Housing: previously homeless/on street/transient, needs housing, has no realistic housing options or only one option, history of violent crime/arson/sex offense (since these offenses are obstacles to obtaining housing).

- Transportation: needs transportation, needs transportation to doctor appointments.

Client and staff focus groups and interviews

Qualitative data were used to supplement the quantitative programmatic data. TIP staff invited current or former TIP clients living in the community to take part in either an interview or a focus group at the community-based organization that hosts TIP. In the urbanized catchments, three focus groups were conducted in English, lasting about 2¼ hours; participants were paid $60. In the two more dispersed catchments, face-to-face interviews were conducted in English or Spanish, lasting about one hour; participants were paid $25. Three separate focus groups of staff, lasting one to two hours, included (a) TIP case managers who work in correctional facilities and in the community, (b) HIV coordinators who work in jails, and (c) infectious disease nurses and case managers in prisons. The evaluator recruited staff by email. To clarify evaluation findings and their interpretation, the evaluator conducted one-hour interviews by telephone with a senior case manager from each site, an HIV coordinator, and an infectious disease nurse – all of whom had taken part in a focus group – and in person with a specialist from the Massachusetts Department of Youth Services were used. Staff participants did not receive a stipend. All focus groups and interviews were tape-recorded.

Analysis

Clients' service needs were analyzed by computing descriptive statistics (frequencies and means) for the data from the Intake record, Detailed Needs Assessment, and Assessment Events. In addition, we summarized client and staff descriptions of client needs in the interviews and focus groups.

To determine the extent to which service utilization was driven by identified needs, we conducted chi-square analysis to determine whether cases where an area of need had been identified at intake were more likely to have an appointment set up, a case management event, or a service procurement event (or any one of the three) addressing that need (Table 4).

Results

Programmatic data were collected for 884 TIP clients whose characteristics are summarized in Table 1. Characteristics of the qualitative study participants are also in Table 1. Seventeen clients took part in a focus group; face-to-face interviews were conducted with eleven others. Although we draw no statistical inferences from the focus group or interview data, for a small number, they were a fair representation of TIP clients. Over 60% were persons of color. Twenty-five staff members took part in a focus group: twelve TIP case managers, seven HIV

coordinators (from jails) and five infectious disease nurses (from prisons). Eight staff interviews were conducted: five with TIP case managers, and one each with an HIV coordinator (jail), an infectious disease nurse (prison), and a specialist for the Massachusetts Department of Youth Services.

There were 1,265 cases involving these 884 clients (a case closed when a client who had been released was re-incarcerated; if the client wanted services again, a new case was opened). Needs assessed at case intake are set forth in Table 2. In 636 cases where any need was identified at intake, the most commonly identified needs were: medical/HIV care (69%) and housing (67%), followed by substance abuse treatment (58%), basic needs (46%), transportation (43%), and mental health treatment (41%).

A total of 702 detailed needs assessments were conducted, involving 476 clients. Results are displayed in Table 3. In most cases (80%), clients were receiving treatment for HIV while incarcerated, and a different 80% planned to return to a health care provider upon release. This included some cases where clients were not currently receiving treatment. In 58% of the cases the client was on prophylactic anti-retroviral medication, and in 75% of cases (92% of those currently on medication and 39% of those not currently on medication), the client planned to take medication after release. (Responses in this section were not limited to cases in which the client was currently receiving treatment or medications, and responses were not mutually exclusive; consequently, the number of valid responses varies, as shown on Table 4). The greatest need associated with medical appointments was transportation (46%). In 22% of the cases the client had no insurance of any kind.

In about half (48%) of the cases the client had a history of mental illness, while in two-thirds of the cases (66%), the client had received mental health treatment. A history of substance abuse was widely prevalent (96% of cases), and in 74% of the cases, the clients had received treatment; however, only 58% of cases were identified as needing transitional substance abuse services. With regard to housing, although clients definitely preferred to have their own home, in most cases they had previously been living with others. In 19% of cases the client had no realistic housing options, and in another 70% of cases they had only one realistic option. For a third (34%) of cases, the nature of the client's offense (mainly violent offenses) posed an obstacle to finding housing.

The level of need at intake was greater in 2003 than in previous years. On the other hand, the number of cases with needs for a particular service did not change appreciably between the intake assessment and the monitoring or case review assessment (not displayed).

In the client and staff focus groups and interviews, descriptions of needs focused on the greatest *unmet* needs. Decent, affordable housing was repeatedly described as the greatest unmet need. The housing shortage is especially severe in Western and Central Massachusetts, and in Boston available housing has declined due to AIDS Housing Corporation funding cutbacks and loss of Section 8 vouchers and is particularly scarce for certain groups: Women and children are excluded from available beds if they are not on Transitional Assistance. There is no long-term housing other than shelters for the chronically mentally ill and chronically homeless. Clients with HIV dementia are considered too needy for HIV housing, but do not fit DMH eligibility criteria. For HIV+ sex offenders and arsonists, halfway houses are not an option, so they become homeless if their families or friends are unable or unwilling to house them.

Three other broad areas of need mentioned often were (a) substance abuse treatment, including detox (“You get kicked out while still sick, they put you right back in the street! No more holding beds for people with no insurance. They’re closing programs.”), (b) transportation, and (c) jobs and education or training to get jobs. A criminal records check poses an obstacle not only for housing, but also for jobs and school, and in one focus group clients exchanged advice on how to get one’s record sealed.

Both clients and staff noted that clients who have been incarcerated need extra guidance and assistance, especially at first, because they have become accustomed to living in a highly structured environment with few decisions to make. For some, just finding their way around a new neighborhood is a challenge, and this can make even simple tasks of daily living daunting; attending to all of their needs is overwhelming. “When you are coming out of prison…, most of the time your life is a mess and, little by little, you have to put it back together.” An HIV coordinator concurred: “They know how to go back to the community and go to a package store. They know how to go back to the community to shoot dope or go to the drug man. What they don’t know how to do on their own when they go back to the community is to go to the first doctor’s appointment, or to pick up their prescription. They don’t know how to go to the AA or to do job finding. The TIP program seems to provide all of those services that handhold the guys that have been incarcerated to give them another shot at doing something that’s right.”

Nearly all cases (95%) involved a first contact before the client was released. Services while incarcerated included helping clients to focus on what they wanted to do after release, assistance to fill out forms/ applications, finding and arranging appropriate housing for clients upon release, discussing and setting up post-release medical treatment and non-medical appointments, and building a trusting relationship.

We examined the extent to which service utilization was driven by identified needs. Appointment setup (38%) and case management (43%) events most commonly addressed health care needs, whereas service procurement events most often addressed mental health needs (44%). In all areas of need – health/HIV care, mental health, substance abuse, housing or transportation – if a need in that area was assessed at intake, TIP case managers were far more likely ($p < .0001$) to set up an appointment or to provide case management services that addressed that need. In every area of need but mental health (n.s.), they were slightly more likely to procure external services addressing that need ($p < .05$)(Table 4).

Discussion

Limitations

Programmatic data were collected for quality assurance, e.g., to see if clients were "slipping through the cracks," rather than for evaluation. Therefore, a number of rigorous research protocols (e.g., mandatory skip patterns, instruction manuals and codebooks) were not built into the system, and inferences drawn from missing answers would be questionable. The problem of missing data affects results in several ways. For many cases, no short-term or long-term needs were identified. TIP case managers reported that this reflects incomplete data entry rather than a lack of needs. Needs assessments were not consistently provided to project staff until after the fall of 2002 when the project protocols were revised. Although we attempted to compensate for missing data by combining needs recorded on the assessment form and on the initial case record, there still appears to be greater need over time. There may be other systematic variation as well in who appears to have the greatest needs.

There was wide variability in the timing of referrals to TIP – some being made immediately upon incarceration without an anticipated release date, which may eventually have been more than a year later, and others being on the day of release – with the average being approximately three months before release. Consequently, the pertinence of needs assessments to realities faced at discharge is likely to vary accordingly.

Conclusions

Clients who are incarcerated and living with HIV have multiple needs that must be met in order to ensure a successful transition to the community. These needs include not only services in the areas of health, mental health, substance abuse treatment and housing, but also – in large part due to the experience of incarceration – a range of services to help them successfully organize and access those primary services, such as planning, advocacy, support and transportation.

The increase in the needs of clients over time could reflect improvement in record-keeping, as more recent cases have more data; staff also noted a trend of clients asking for more services as word gets around about what TIP can do. Needs of individual cases, on the other hand, remained consistent from intake to follow-up. Despite staff focus on *unmet* needs in the focus groups, and their concern about possible failure to document *ongoing* needs that are being met (for example, if a person needs transportation but receives a free bus pass), we infer that most case managers did include ongoing needs. Furthermore, this consistency of needs lends credence to a view expressed by most case managers and clients that even though needs are being met, they are ongoing needs that are unlikely to end – certainly not in the short term (six months is considered to be "short term" for clients addressing substance abuse). Therefore, they reasoned, case duration is best determined on a flexible case-by-case basis, rather than by a firm policy.

The increase in the number of clients with medical needs after release may occur because some inmates elect to forego treatment while incarcerated (58% currently on medication vs. 75% planning to take meds after release).

It is curious that many clients who did not report a history or diagnosis of mental illness had received mental health services. The question did not distinguish whether services were before or during incarceration. There is probably more stigma attached to having a history of "mental illness" than to receiving mental health services. This could indicate that previously undiagnosed mental illness is being treated during incarceration for the first time. Or, it may mean that treatment is provided for conditions that do not officially qualify as "mental illness." Staff reported that formal mental health treatment was rare during incarceration, and posited that any visit with a clinical social worker or psychologist – e.g., routine evaluation for classification of danger in order to determine what level of security is required – might be perceived as mental health treatment. One case manager, in order to downplay possible deterrence of stigma, rephrases the question to ask if the client has ever had "counseling."

A different pattern emerged with respect to substance abuse needs: 96% were identified at intake as having a history of substance abuse, 74% had received treatment, 78% planned to receive treatment after release, yet only 58% were identified as having a need for transitional substance abuse services. According to case managers, if a client denied any particular need or wished no assistance in that area, the case manager would not record that need, even if their own estimation differed. This corresponds with observations that TIP case managers, as well as staff inside, devote a great deal of effort to encouraging plans for substance abuse treatment on release. From the vantage of their sobriety in the structured correctional environment, clients tend to underestimate the challenge of staying clean and sober when they return to the community, especially if they return to the same environment where they were abusing substances.

Clearly, one of TIP's greatest challenges is procuring appropriate housing. For a third of clients no viable housing option or expect to go to a homeless shelter. Since 2001, Massachusetts, like many other states, has experienced fiscal shortages resulting in large cutbacks in social services, including housing. Funding challenges have also plagued the U.S. Department of Housing and Urban Development. These cutbacks have exacerbated an already chronic lack of publicly funded housing. Housing shortages have particularly impacted clients being released from correctional facilities, posing an additional hurdle for TIP case managers in obtaining appropriate housing placements for clients. When parole has been approved contingent on an appropriate placement, this difficulty can delay release or result in sub-optimal placements. On the other hand, when residential substance abuse treatment is available, at times an inmate will agree to it half-heartedly, just to get out. Nonetheless, this situation is probably better than when a sentence is "wrapped," and the inmate cannot legally be detained no matter what housing options are or are not available. Staff "inside the wall" have observed (as reported by Kurkjian, 2004, with regard to perpetrators of violent crimes and sex offenses[15]) that more clients fall into this category than in the past, and are being released without conditions of parole. In winter, it may be necessary to go to a shelter just for survival, but it can be extremely difficult for addicts to remain clean and sober in a shelter environment. The same may be said for any setting – housing with family or friends – if the host is an active user.

Transportation was the most commonly listed need related to medical appointments, and during interviews and focus groups clients frequently mentioned its crucial importance.

The finding that clients with more cases had *lower* medical and housing needs was counter-intuitive. When asked about this finding, one TIP case manager posited that TIP clients who were re-incarcerated may have expected to return to their existing primary care provider and housing situation after release. Possibly they still require case management due to pending legal proceedings and to arrange for substance abuse treatment (relapse being the most likely reason for return).

Also impressive, although not surprising, is the very high correlation between assessed needs and case service events addressing those needs, indicating that needs that have been identified are being addressed appropriately. The most notable exception – a lack of association between assessed mental health needs and procurement of mental health services – generated several possible explanations. One is that the procurement efforts of TIP staff for those with greater need do not result in a correspondingly greater amount of mental health services. TIP staff have reported that overly restrictive eligibility criteria for services from the Department of Mental Health and the Veterans Administration pose an obstacle to procuring mental health services for all but the most severely mentally ill. Another possibility is that mental health needs may have been under-assessed. This interpretation gains credence from the observation that more clients had received mental health services than had been identified as having a history of mental illness. (On the other hand, both of these data did contribute to our measure of mental health needs.) Although the needs assessments were recorded by the TIP case managers, to the extent they relied on clients' self-report, a third possibility is that some clients did not objectively report their mental health status.

In summary, incarcerated persons living with HIV, when they are released, have multiple needs in the areas of health care, mental health, substance abuse, housing and transportation. These are complicated by the adjustments required upon re-entry in the community. These findings suggest that mental health services, substance abuse treatment, housing and other support services in the community should be expanded for former offenders living with HIV.

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Table 1. Description of TIP Clients and Study Participants

	Programmatic Data (n = 884)		Client Focus Group or Interview (n = 28)		Staff Focus Group or Interview (n = 25[a])	
Variable	**%**	**(n)**	**%**	**(n)**		
Sociodemographic Characteristics						
Gender						
Male	76	(674)	54	(15)	32	(8)
Female	24	(210)	43	(12)	68	(17)
Transgender	0	(0)	4	(1)	0	(0)
Ethnicity/Race						
African American	23	(203)	15	(4)	4	(1)
Hispanic	29	(257)	41	(11)	16	(4)
White	38	(339)	43	(12)	80	(20)
Cape Verdean/Portuguese	4	(37)	4	(1)	0	(0)
Native American	1	(9)	0	(0)	8	(2)
Other or unknown	5	(39)	0	(0)	0	(0)
Age *(n=882)*[b]	(mean = 38.7, sd = 7.4)					
17-29	10	(87)	0	(0)	4	(1)
30-39	46	(406)	32	(9)	16	(4)
40-49	37	(323)	54	(15)	28	(7)
50-79	7	(66)	14	(4)	52	(13)
Married or Committed Relationship[b] *(n=451)*						
No	76	(342)	52	(14)		
Yes	24	(109)	48	(13)		
Health history[b]						
Hepatitis C *(n=480)*	58	(278)				
Developmental Disability *(n=415)*	11	(45)				
Mental Illness *(n=435)*	48	(209)				
Substance Abuse *(n=423)*	96	(404)				
Number of Cases						
One	68	(602)				
Two	23	(200)				
Three-Five	9	(82)				

[a] *Actually, 26, but one participant did not provide demographic data.*
[b] *As of case intake. For clients with multiple cases, the first case intake was used.*

Table 2. Areas of Greatest Need at Case Intake (of 636 cases with needs identified)

Variable	%	(n)
Medical/HIV care	69	(437)
Housing	67	(425)
Substance abuse treatment	57	(363)
Basic needs (e.g., food, clothing)	46	(295)
Transportation	43	(274)
Mental health treatment	42	(264)

Table 3. Detailed Intake Needs Assessments (needs assessments = 702 [a])

Need	%	n	Valid Answers
Medical Care			
Receiving medical care while incarcerated	80	(489)	*613*
Plan to return to former provider in community	80	(426)	*535*
Has appointment	41	(202)	*494*
Amenable to referral to doctor	90	(182)	*202*
Needs assistance			
Transportation	46	(324)	*702*
Accompaniment	20	(140)	"
Reminder	18	(123)	"
Completing forms	16	(110)	"
Translation	6	(42)	"
Medication			
Took HIV medicines regularly before incarceration	41	(248)	*610*
Took meds regularly during incarceration	67	(359)	*539*
Now on prophylactic/antiretroviral meds	58	(331)	*568*
Plan for meds on release	75	(402)	*534*
Arrangements for meds on release	63	(278)	*439*
Needs reminder to take meds	30	(98)	*322*
Insurance			
Massachusetts Health (Medicare/Medicaid)	58	(406)	*701*
Other	20	(144)	*702*
None	22	(152)	"
Mental Health			
History of mental illness	47	(304)	*645*
Received MH treatment	66	(270)	*412*
Plan for MH treatment on release	69	(265)	*385*
Need MH referral	50	(151)	*307*
Need MH services during transition	45	(156)	*350*
Substance Abuse			
History of substance abuse	96	(599)	*625*
Received SA treatment	74	(412)	*554*
Need SA referral	78	(456)	*584*
Need SA services during transition	56	(309)	*547*
Housing			
Offense is housing obstacle	34	(237)	*702*
Sex offense	6	(45)	"
Arson	2	(11)	"
Violence	29	(205)	"

	Prior Housing		Housing Preference		Realistic Option	
	% [b]	(n)	% [b]	(n)	% [b]	(n)
Own	18	(123)	31	(217)	7	(52)
Spouse/partner	18	(127)	10	(69)	8	(58)
Family	20	(137)	9	(64)	16	(112)
Friend	14	(95)	3	(20)	7	(47)
Shelter	10	(70)	4	(28)	15	(103)
Residential substance abuse treatment /halfway /sober house	2	(14)	31	(221)	35	(247)
HIV residence/medical/supported	1	(8)	3	(18)	3	(21)
Other, Single Room Occupancy (SRO)	1	(10)	5	(34)	6	(42)
None (or homeless)	10	(72)	13	(90)	17	(118)

[a] *Clients = 476*

[b] *Total exceeds 100% because more than one answer was allowed.*

Table 4. Association of Needs Addressed by TIP Events with Needs Assessed (cases = 1,265)

	Cases with Need Assessed									
	Medical Care		**Mental Health**		**Substance Abuse**		**Housing**		**Transportation**	
Cases with Recorded Event[a] Addressing Need:	49 (620)		49 (623)		61 (776)		62 (785)		45 (572)	
	% (n)	**p**	**% (n)**	**p**	**% (n)**	**p**	**% (n)**	**p**	**% (n)**	**p**
Appointment Setup	41 (257)	<.0001	28 (170)	<.0001	32 (245)	<.0001	32 (245)	<.0001	21 (120)	<.0001
Case Management	61 (378)	<.0001	46 (285)	<.0001	46 (351)	<.0001	52 (102)	<.0001	42 (241)	<.0001
Service Procurement	5 (28)	.003	5 (31)	n.s.	1 (10)	.04	2 *(14)	.02	2** (11)	.0004
Any Event[a]	71 (441)	<.0001	55 (341)	<.0001	58 (447)	<.0001	60 (468)	<.0001	48 (272)	<.0001

[a] *Needs addressed were recorded only for appointment setup, case management, and service procurement events*