Department of Public Health
Community Mental Health Services

Identifying Factors That Contribute to Longer Term Community Tenure for L-Facility Discharged Clients

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Abstract

It was in the interest of San Francisco Community Mental Health Services to evaluate the efficacy of its policy to move as many clients as possible from sub-acute facilities to the community. To this end, Quality Management staff employed a mixed-method design to ascertain which client demographic, clinical, and treatment factors contributed to longer-term community tenure. The study pool consisted of 128 clients selected from all clients discharged from an L-Facility during 1997 and 1998. This evaluation included: review of Billing and Information System (BIS) demographic, diagnostic and service use data; chart abstracts of clinical data for 256 institutional and community charts, Semi-structured interviews with a convenience sample of 29 clients from the study pool, and a focus group of institutional and community provider staff. The results indicate that clients who "failed " to remain in the community for at least 24 months were more likely to be male, African American, and younger; have moderate to severe substance abuse issues and medical problems; to be less engaged in social activities, daily self care activities or employment; to have less days spent in sub-acute facilities and more days in acute services. Qualitative data provided this evaluation with a variety of inputs related to the need for social activities, quality professional relations, physical health education and linkage, more integrated linkage between community and institution. The authors of the evaluation identify a number of issues that could improve the overall quality of care and outcome for long-term care institutionalized clients.

Introduction and Purpose of this Evaluation

During the last decade, San Francisco Community Mental Health Services has sought to achieve two objectives within its larger goal of providing quality mental health services: reduction of institutional bed utilization and successful community tenure for its client population. These objectives are part of what has become standard practice among nationwide mental health systems of care. While the supporters of de-institutionalization have included both the consumers of mental health services and the behavioral healthcare industry, the actual, long-term impact of de-institutionalization on individual lives remains the subject of a number of studies. More recently, the philosophy of wellness and recovery has entered the lexicon of community mental health services. Advocates and consumers are seeking to promote the idea that persons with severe and chronic mental illness can and do integrate into the mainstream of community life.

Consistent with the above described objectives, San Francisco Community Mental Health Services embarked on two significant services ventures in 1996. San Francisco County opened the Mental Health Rehabilitation Facility (MHRF). The design and implementation of the MHRF was an effort to bring clients closer to the community in which they hoped to reside and to intensify rehabilitation efforts to move the client to the community. The second major initiative was the implementation of the Assertive Community Treatment model. These programs, known as Single Points of Responsibility (Sprees) in San Francisco are founded on an intensive, twenty four hour/ seven day per week community treatment model begun in Wisconsin in the mid 1970s. Beginning in 1996, 400 clients were enrolled into the Sprees.

Evaluation Question

This exploratory quality improvement evaluation seeks to identify possible factors that impact community tenure for individuals who are discharged from long-term care institutions. This evaluation considers a wide range of variables included in table 1. The evaluation seeks to correlate these factors with clients' tenure in the community following discharge from an L-facility. For the purpose of this evaluation, recidivism is defined as return to an L-facility and community tenure is defined as the time elapsed between discharge from an L-facility and return to an L-facility. At the time of this study, the clients in the study pool have been tracked for at least a 24-month period. Those who did not require further long-term care during this 24-month period are considered non-recidivists. "Acute" psychiatric episodes were not considered recidivism unless accompanied by an immediate return to an L-facility. "L-facilities" in the State of California are also know as Institutes for Mental Diseases (IMD) and are generally licensed as sub-acute psychiatric skilled nursing facilities. The study seeks to better understand whether longer-term community tenure could also be termed as "success". The counter argument poses that de-institutionalization and the client's ability to stay outside an L-facility do not necessarily imply an efficacious outcome for the client.

Table 1 – Study variables

- **Demographic**
- **Diagnostic**
- **Service assignment and utilization**
- **Residential placement**
- **Substance use**
- **Medical problems,**
- **Cognitive impairment,**
- **Individual ability to complete Activities of Daily Living**
- **Vocational involvement**
- **Social engagement**
- **Behavioral problems**
- **Psychiatric symptoms**
- **Medication effectiveness and compliance**

Sampling Criteria

The study population initially consisted of 340 individuals with serious mental illness who were released from L-facilities during the calendar years 1997-98 and were San Francisco Community Mental Health Services' clients. The index discharge was defined as the first discharge from an L-facility during those years.

Included in this count were:

1. Clients who were discharged to community residential and outpatient facilities.
2. Clients who left the L-facility Against Medical Advice (AMA) or were Absent Without Leave (AWOL).

It is important to note that an episode was defined as contiguous days within one or more sub-acute psychiatric care facility. This is germane to the chosen time period as a significant sample of the clients released from the San Francisco Mental Health Rehabilitation Facility (MHRF) were transferred from other out of county facilities prior to their discharge in 1997 and 1998. The vast majority of the clients who were initially transferred to the MHRF had contiguous episode in an out of county facility

Excluded from this count:

1. Clients who were re-admitted to an L-facility within seventy-two hours.
2. Clients who were discharged to an acute psychiatric facility and, without interruption by any presence within the community, re-admitted to an L-facility.

From the above sample, a random fifty-percent (170 individuals) were then included in the study.

The following refinement of criteria was then added to select the final sample:

1. Clients who were discharged to sub-acute non-psychiatric medical facilities were included.
2. Clients who were discharged from one of four select L-facilities, which together accounted for more than 90% of the discharges. A few L-facilities were excluded due to their distance from San Francisco County.

Early in the selection process it was discovered that a discharge was often a transfer to another sub-acute psychiatric institution and not a community discharge. To insure that selected clients met the above criteria, a careful review of the discharge history was manually completed to obtain the final sample of 128 clients. This manual inspection was completed through a review of the CMHS Billing and Information System (BIS) individual service utilization report, also know as the "face sheet" or the MHS 140.

Methodology and Data Collection

The study employed a mixed method design using four data sources and collection methods. Some of the succeeding sections contain a more complete description and discussion of methods. In brief, the varying methodologies are described below:

1. BIS: the CMHS Billing and Information System was queried for demographic, discharge diagnosis, lifetime service tenure in the CMHS system, twenty four month pre-index episode service utilization and 24 month post-discharge service utilization for ALL of the 128 study eligibles.

2. A chart abstract tool (see appendix D) was created to assess client status during the index institutional stay and at 12 months post discharge at the community program. The tool was designed to rate the frequency of mention (see appendix E for rating scale) and thereby the focus of care in both the institutional chart and the community service chart for the following areas: substance abuse, physical health problems, cognitive impairment, activities of daily living (ADL) and self care ability, socialization, medication adherence and effectiveness, and residential placement. Each item was rated in the institutional chart for up to one year prior to discharge to assess the status at discharge and in the community chart for up to one-year following discharge. Three additional items, impact of behavioral problems, presence of psychiatric symptoms, and engagement in employment, vocational and/or educational activities were also rated from the community charts. The chart abstract tool was piloted on 10 charts and cross-rated by two raters. Modifications of the tool were made based on pilot results. The chart reviewers periodically cross-rated each other's review for reliability. Charts were reviewed for the entire sample.

3. A semi-structured client interview protocol (see appendix E) was created to interview a convenience sample of twenty-nine clients. The sampling selection attempted to achieve representation from all demographic categories, index discharge institutions, community discharge programs, and recidivist and non-recidivist clients. Three clients were interviewed in their native Chinese language. Clients were recruited from the sample with assistance from the current provider of service. A $20.00 stipend was provided for all participants. Participants were required to have some ability cooperate with the interview, to be relatively verbal and not floridly psychotic during the interview. Of attempted recruits, 3 potential participants refused. Only one client left the interview before completion, this occurred during the pilot phase. The interview protocol was piloted on four clients. Modifications of the tool were made based on the pilot results. The interviews were conducted by a clinical psychology doctoral student and experienced interviewer from the Saybrook institute. The essential focus of the interview was to survey what study participants perceived as helping or not helping in staying out of long-term care. Each of the interviews was taped and transcribed. Transcription themes were abstracted and categorized by study authors and interviewer.

4. A focus group protocol with open ended but targeted questions was created (see appendix G) and executed with a group of 16 providers from two institutional care and 6 outpatient, residential service and intensive case management programs. Participants' comments were summarized by a recorder and entered into a Word file during the actual focus group. Participants were asked to challenge any misrepresentations. The focus group record was reviewed and analyzed for themes and categorization.

Findings

Findings are presented for each methodological inquiry:

Billing and Information System Data

There were a number of challenges to extracting and using BIS services data. A complete discussion of these challenges is appended in appendix A. In general, there appears to be very few problems in the service data after 1993. The limitations and problems with the BIS data prior to 1993 limited our ability to assess clients' complete service utilization history. Because relatively few problems have emerged in the more recent data, we limited our analysis to services after 1994. A number of issues related to the query are discussed below:

- In 1991 CMHS converted to Insyst from the previously used billing system. Despite efforts made to transfer existing data over to Insyst, not all of the data was successfully converted. As a result, service data prior to 1991 is sparse.

- Units of service in the Episodes Table represent varying time units specific to service modality**.** The service units in the Episodes Table that correspond to an episode can not be translated into precise units of time for most of the service modalities. One unit of service represents different units of time depending on the service modality.

- Units of service did not always equal the length of episode for Mode 5 services. Several episodes had no corresponding service units. The discrepancy was seen in almost all of the service modalities. Apparently it is not unusual for an IMD or SPR episode to have no units of service recorded, but there is no clear explanation why there are episodes in the other modalities with no corresponding units of service. It is most likely due to data entry errors.

Demographic Factors

Table II on page 7 provides demographic and discharging L-facility frequency distribution for all clients in the sample. These factors were also cross-tabulated for recidivist and non-recidivist status.

In comparing this cohort to the demographics that are served within CMHS, Caucasians appear to be overrepresented, African Americans approximate their numbers in the general CMHS population and Latinos and Asian/Pacific Islanders appear to be underrepresented. There were more males in this cohort as compared to the general CMHS population

Table II BIS Demographic, Diagnostic, and Facility Data

	Recidivist	*% Recidivist within category value*	*NonRecidivist*	*% Nonrecidivist within category value*	TOTAL	*% of Total Sample*
N	30	***23%***	98	*77%*	128	
Gender						
male	18	***27%***	48	*73%*	66	*52%*
female	12	*19%*	50	*81%*	62	*48%*
Age Group						
21-30	4	***44%***	5	*56%*	9	*7%*
31-40	4	***22%***	14	*78%*	18	*14%*
41-50	10	***30%***	23	*70%*	33	*26%*
51-60	4	*13%*	27	*87%*	31	*24%*
61-70	6	*30%*	14	*70%*	20	*16%*
71 and older	2	*12%*	15	*88%*	17	*13%*
Ethnicity						
White	15	*21%*	55	*79%*	70	*55%*
African American	13	***42%***	18	*58%*	31	*24%*
Latino/Chicano	0	*0%*	6	*100%*	6	*5%*
Asian/Pacific Islander	2	*15%*	11	*85%*	13	*10%*
Unknown	0	*0%*	7	*100%*	7	*5%*
2 or more Ethnicities	0	*0%*	1	*100%*	1	*1%*
Primary Dx						
Schizophrenia (excluding schioaffective)	10	*24%*	31	*76%*	41	*32%*
Schizoaffective Disorder	14	***26%***	39	*74%*	53	*41%*
Mood Disorder	4	*17%*	20	*83%*	24	*19%*
Other	2	*20%*	8	*80%*	10	*8%*
Language						
English	28	*25%*	84	*75%*	112	*88%*
Spanish	0	*0%*	2	*100%*	2	*2%*
Chinese Dialect	1	*25%*	3	*75%*	4	*3%*
Filipino Dialect	0	*0%*	1	*100%*	1	*1%*
Vietnamese	0	*0%*	1	*100%*	1	*1%*
Other	1	*14%*	6	*86%*	7	*5%*
Cantonese	0	*0%*	1	*100%*	1	*1%*
Facility						
MHRF (8812RF)	22	***29%***	53	*71%*	75	*59%*
San Mateo LT (88731)	2	*18%*	9	*82%*	11	*9%*
Canyon Manor (99331)	3	*13%*	20	*87%*	23	*18%*
Crestwood-Vallejo (99461)	3	*16%*	16	*84%*	19	

The % within category value field shows the distribution of recidivists and non-recidivist within each of the demographic categories (e.g. 27% of males were recidivists and 73% were non-recidivists). The % of total field shows the distribution of the demographic variable for the whole sample (e.g. 52% of this sample is male and 48% is female). **High rates of recidivism are in bold.**

Recidivism

Note that recidivist percentages appear in bold on table II on the previous page

- Overall, 30 individuals or 23% of the sample returned within twenty-four months of discharge from an L-facility. For the purposes of this report, this group is referred to as the "recidivist" group. 37% of the recidivists returned to the L facility within 3 months. 66% of the recidivists returned within one year (see summary in Table III below).

- Amongst the demographic variables, males, African Americans, and younger appear to be at the greatest risk for recidivism.

- Overall 32% of the sample had a schizophrenia diagnosis and 41% were diagnosed as schizoaffective. These diagnoses were more likely to return to an L-facility within twenty-four months than clients with a mood disorder diagnosis.

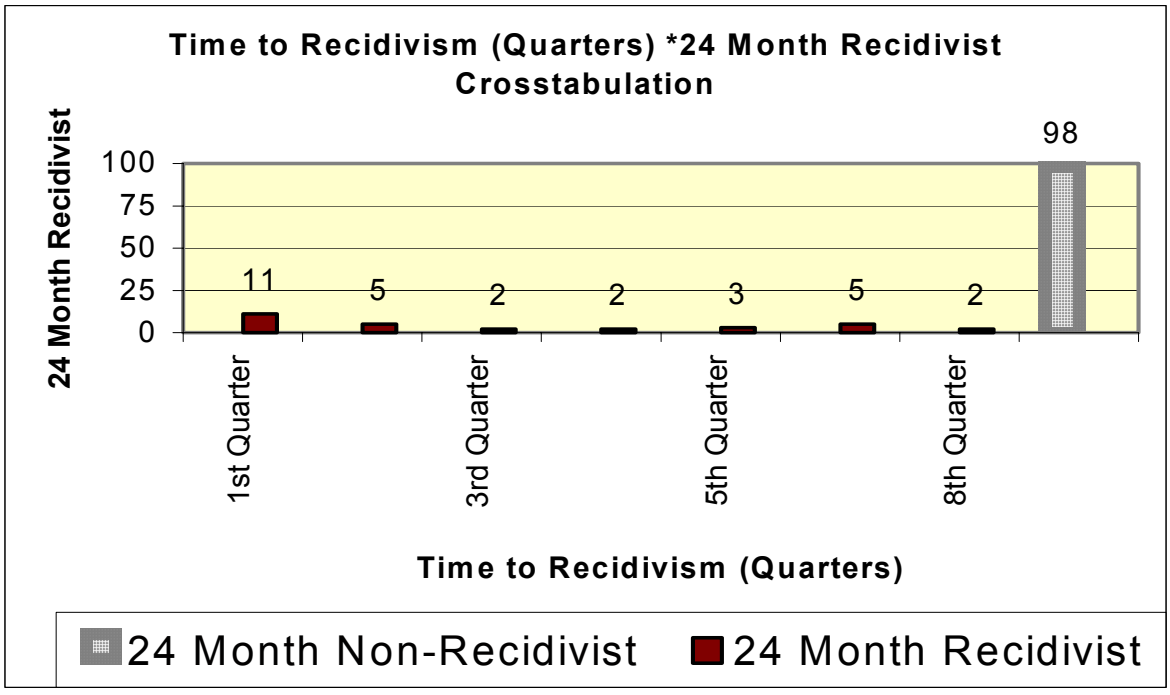
- The number of non-English speakers was too insignificant to derive any inference.

- Clients from the Mental Health Rehabilitation Facility had a greater risk of returning to an L facility within twenty-four months. It is also important to note that this facility was in the first year of operation with a mandate to transition clients to the community quickly.

Table III

Time to Recidivism (Quarters) *24 Month Recidivist Cross-tabulation

Non Recidivists = 98 Recidivists = 30



Service Utilization

For the entire sample of 128 clients, service utilization prior to and subsequent to the index episode was reviewed. There were significant differences in pre and post-index service utilization patterns between the recidivist and non-recidivist clients. The tables on the following pages provide details of the service utilization patterns. Following common survival analysis protocol, the service utilization data for each of the recidivist clients was truncated on the date of recidivism whereas for the non-recidivists, the data

spanned the entire 24-month post-discharge period. A complete explanation as to why a two-year period prior to the index episode was chosen is provided in appendix A.

Pre-index Service Utilization

On average recidivists used 62% more pre-index episode acute hospital hours, 26% more Acute Diversion hours and had 118% more crisis hours. In contrast recidivists had 44% fewer IMD hours and 28% fewer residential treatment hours (See Table IV below).

Table IV

Services 2 years prior to
Index Admission Date for clients whose admission date was after 1/1/96*
(Services are noted in hours)

Full Sample (n=93)

Program Evaluation	Mean	Min	Max	Median
Acute Inp	2818.43	144	10248	2328
ADU	775.11	24	3120	432
Crisis	63.29	4	470	39
DayTx	1204.31	16	4640	804
IMD	7377.00	96	17928	5484
OP	101.30	1	478	66
RT	3342.86	72	9552	3168
SPR	16.63	1	49	15

Recidivists (N=22)

Program Evaluation	Mean	Min	Max	Median
Acute Inpt	3961.41	1704	10248	2952
ADU	890.40	24	3120	804
Crisis	105.49	7	470	82
DayTx	2128.00	96	4640	1888
IMD	4603.20	168	13752	4800
OP	126.97	6	342	70
RT	2568.00	264	4632	2712
SPR	12.75	13	13	12.75

Non-Recidivists (n=71)

Program Evaluation	Mean	Min	Max	Median
Acute Inpt	2444.77	144	7848	2064
ADU	707.29	24	2520	384
Crisis	48.98	4	195	36
DayTx	1036.36	16	2720	804
IMD	8301.60	96	17928	6564
OP	93.23	1	478	61
RT	3585.00	72	9552	3180
SPR	17.60	1	49	10

*The above analysis includes approximately 75% of the sample (22 recidivists and 71 non-recidivists). We sought to compare services over equivalent time periods for all clients. Several problems arose while extracting data from the BIS, primarily in services prior to 1994. For this reason, we included clients whose index admission date was after 1/1/96 so that each client would have a full two years in which relatively accurate and reliable services were recorded.

Historical Tenure in the System

In all, both recidivists and non-recidivists had an overall mean of about 11 ½ years of tenure in CMHS until discharge date. There was a difference however in the medians; recidivists had 10.4 years versus 12.5 years for non-recidivists (see Table V below).

Table V

Length of Time in System from index discharge date (in days)

	Avg	Min	Max	Median	N
Recidivists	4210.63	1547	8684	3803	30
Non-Recidivists	4168.51	59	20916	4569	98
Full Sample	4178.38	59	20916	4532	128

The length of time in the system was computed by subtracting the opening date of clients first episode from their IMD index discharge date

Index Episode Length of Stay (LOS)

The mean LOS for recidivists' was 470 days compared to non-recidivists at 793 days or an average of 41% fewer days for recidivists. The median difference was similar (See Table VI below).

Table VI

Length of IMD Index Episode (in days)

	Avg IMD LOS	Max IMD LOS	Min IMD LOS	Median	N
Recidivists	469.87	1838	10	238	30
Non-Recidivists	792.69	9876	29	411	98
Full Sample	717.03	9876	10	401	128

LOS was calculated by subtracting the opening date of the IMD from the closing date of the IMD contiguous IMD episodes

Post-index episode service utilization

The differences in post-index service utilization are also significant. On average, recidivists used 54% more acute hospital inpatient hours and 52% more crisis hours. In contrast, recidivists used 48% less ADU and 66% less residential treatment (see Table VII next page).

Table VII

Services 24 months post-index discharge

Recidivists (N=30)

	Mean	*Min*	*Max*	*Median*	*N*
Acute Inpt	1870.8	336	5280	1356	20
ADU	465.6	48	1008	576	5
Crisis	33.85	5	170	20	25
DayTx	560.8	16	1832	324	10
OP	55.96	2	301	30	29
ResTx	1830.55	72	7656	1080	11
Socialization	*No Services*				
SPR	123.04	3	342	107.97	13

Non-Recidivists (N=98)

	Mean	*Min*	*Max*	*Median*	*N*
Acute Inpt	1212.57	24	3960	696	21
ADU	904	480	1680	768	6
Crisis	22.32	3	77	18.71	30
DayTx	1813.07	64	7032	1408	30
OP	75.97	1	708	35.75	96
ResTx	5467.43	648	15360	4728	21
Socialization	148	68	228	148	2
SPR	304.4	10	1728	256.42	47

Full Sample (N=128)

	Ave	*Min*	*Max*	*Median*	*N*
Acute Inpt	1533.66	24	5280	1128	41
ADU	704.73	48	1680	600	11
Crisis	27.56	3	170	20	55
DayTx	1500	16	7032	1216	40
OP	71.33	1	708	33.5	125
ResTx	4217.25	72	15360	3600	32
Socialization	148	68	228	148	2
SPR	265.11	3	1728	199.63	60

Discussion

Further analysis through logistic regression and systematic examination of BIS findings will be important. It appears that there are a number of salient demographic and utilization patterns among recidivists.

- African Americans, males and a younger cohort are at greatest risk for recidivism.
- Following discharge from sub-acute institutions, individuals are at greatest risk earlier, within the first few months of their community tenure.
- And perhaps most salient, we found a very high correlation between service utilization and recidivist patterns: recidivist clearly use more acute services, less outpatient services and have much shorter pre-index and index length of stay in the IMD.
- Perhaps the most relevant question in these findings is whether longer IMD stay predicts community tenure.

Chart Data

Two charts were reviewed for each of the 128 individuals: the institutional chart and community chart. The chart abstract targeted the following areas: physical health, substance abuse, cognitive impairment, engagement in socializing and group activities, Activities of Daily Living, residence at discharge, medication adherence and effectiveness. Client medication regimen at discharge and post discharge was also recorded but is not reported here. *The discussion section (below) will consider a number of caveats related to the chart data.* Each domain was rated on a four point scale, e.g., very much, moderate, minimal, or not at all. There was also a "could not determine" rating. For the purposes of this data report, the findings are presented as dichotomous outcomes, as either, "high" or "low" impact, focus or engagement. Comparisons are made between L facility and community chart data as well as between recidivists and non-recidivists. The percentage for each result is presented in a table in appendix E**.**

Residential Placement

The great majority of clients had a planned placement (89.8%) at discharge; 12.1% of this group returned to the L-Facility. 11 clients went AWOL and 1 left AMA; one half of this group returned to an L-Facility within one year. For one individual the discharge status could not be determined.

Primary residence at discharge was recorded as Residential Care Facilities (RCF) for 44% of the sample. The actual recorded residence at 12 months post discharge was RCF for 32% of the sample. Only 5% of the one-year post-discharge RCF clients were recidivists. A number of residential placements with very small numbers had no recidivism. Given the larger numbers of RCF placements and the relatively low rate of recidivism, it appears RCFs may be a significant contributor to longer-term community tenure. *Note that the above data may need further verification.*

22.7% were discharged to residential treatment programs, 10.3% were sent to acute medical care facilities and 3.1% to other non-psychiatric skilled nursing facilities. It was determined from the community chart review that 6 of these 128 clients were deceased by 1 year post-discharge. All 6 of these clients belonged to the group that were discharged to acute or sub-acute medical care facilities and all were older than 60 (4 of them were older than 70). 9 individuals were discharged to independent living situation either alone or with others; none of these individuals returned to the L-facility.

Impact of Physical Health Problems

Overall, the impact of physical health problems increases in the community for recidivists and non-recidivists alike. The rate of recidivism increased from 20% of high impact of physical health problems as represented in the L-facility chart to 40% in the community chart. There was also a higher association of

high impact in physical health problems for recidivists at 40% versus 29% for non-recidivists in the community chart.

Degree of care focus for Physical Health problems

There was a decrease in the focus of physical health care from the L- Facility to the community. In the community chart, recidivists had a slightly higher focus on physical health care.

Substance abuse focus:

Overall, between 21 to 24% of the entire sample of institutional and community charts indicated a high focus on substance abuse problems. In both L-facility and community charts, recidivism was significantly higher for those who had high focus of substance abuse problems when compared to non-recidivists.

Cognitive Impairment Focus

Overall there appears to be greater focus on cognitive impairment in the community versus the institution. However, cognitive impairment did not appear to associate with recidivism.

Social Activity

About one-third of the sample appears to be highly engaged in social activities in both the L Facility and community. It appears from the Community chart that recidivists are less likely to be highly engaged in social activities (20%) than non-recidivists (35%).

Activities of Daily Living (ADLs)

It was notable that 42% of clients could not be assessed for their engagement in activities of daily living in the community chart. 41% of non-recidivist versus only 13% of recidivists were highly engaged in ADLs.

Medication Effectiveness

Overall, medication effectiveness was evenly divided between low and high effectiveness in both the institutional and community charts. Lower medication effectiveness in general appears to be associated with recidivism. It was not possible to discern any documentation of effectiveness in 30% of the community charts.

Medication Compliance

It was clear that higher medication compliance and cooperation was much greater in the L-facility chart. The degree of compliance decreases significantly, especially for recidivists, in the community chart.

Note that the next three domains were only evaluated in the community chart. In the initial design of the chart abstract tool, it was assumed that these areas would be of greater relevance in the community.

Behavioral Problems

Higher focus on behavioral problems was associated with recidivism

Psychiatric Symptoms

63% of recidivists were rated as having moderate to high focus on psychiatric symptoms.

Employment, Educational and Role Functioning

Recidivists did worse on this rating. Only 20% were highly engaged in employment, education or role functioning versus 31% for non-recidivists.

Discussion

The chart review of 128 institutional and 128 community charts provides a number of *indirect* findings that may have significance regarding client outcome and quality of care. There are also a number of caveats. Both are noted as follows:

Documentation Quality

There was significant variation in the consistency of organization and focus of documentation between the institutional and community chart. In general. the institutional charts were very well ordered. The required information was easy to access and identify. It is very apparent from chart documentation that institutional providers have greater opportunity to control the client's environment and assess all facets of the client's physical status, mental status and behavior. Although there is a degree of standardization in community charts, the specifics of what is documented is not consistent across the system and perhaps even within programs. There were a number of areas in the community chart where assessment of the client's status and progress was not possible. In the L facility charts, the range of clients for whom we were *unable* to assess impact in any particular domain was 1 to 6%. This compares with the community charts where the range was from 13 to 67%. It could be argued that if the provider does not document in a particular area then it is not a problem. It is important to acknowledge that twenty-four hour care is by definition more intensive care and therefore more comprehensive in its scope of intervention and documentation.

- ***The above findings suggest that there may be value in standardizing certain aspects of clinical documentation in the community chart. The above findings indicate an association between various behavioral and clinical domains and recidivism. Consistent review and documentation of these domains could serve as flags for potential problems and risk for acute hospitalization and return to a sub-acute facility.***

Quality and Intensity of Services Contact

It was not always possible to assess the client for a full twelve months post discharge. Some clients appear to have had a delay in their linkage with a provider; the client may have changed providers or were marginal in their engagement with the provider resulting in either a brief episode or an episode with few service contacts.

- ***Highlighting lack of linkage and response with provider could also serve as another flag to the provider and system for at risk clients.***

Validity of Documentation

For the purposes of this report, evaluation of clinical status and care was essentially by proxy. Review of documentation does not substitute for a direct evaluation of the client. Clinical documentation assumes that the provider has provided a reasonably accurate and reliable assessment and record of clinical status and care. Imprecision in documentation is unavoidable. The study authors were required to exercise a judicious degree of interpretation. While the task is somewhat subjective, care was taken to standardize the coding to the extent possible (see coding tool in appendix F). This included specifying the coding scheme in detail and then cross rating a sample of charts.

Direct Findings

The chart data provides confirmation of a number of expected findings. Recidivism appears to be more associated with physical health problems, substance abuse, severe psychiatric symptoms, behavioral problems, lesser medication effectiveness, much greater medication non-compliance, poorer employment

engagement, less engagement in social activities and ADLs. Perhaps most salient in these findings was the percentage of clients who did not achieve moderate to high degrees of medication effectiveness. Even more significant was the percentage of clients who were non-compliant with medication.

Medication Effectiveness

It is important to note that the assessment of medication effectiveness may be the result of system wide provider reporting style and not a true representation of clinical efficacy. Lack of medication effectiveness may also underscore the need for comprehensive approaches with this, the most chronic of community mental services users.

- ***It is important to consider that with this clinical population, it may only be possible to evaluate medication effectiveness in the larger context of multi-disciplinary and multi-modal interventions.***

Another conjecture is the "typical" versus "atypical" effect. It is notable that in the interview cohort, clients report more favorable responses to their current medication regimen. This could be an effect of the greater diffusion of atypical medications overtime which may also correlate with the interviews which occurred in the past year as opposed to the chart reviews which occurred two to three years ago. Evaluation of typical versus atypical effect is beyond the scope of this report.

Interview Data

Methodology

A number of survey methods were considered. As required by the State Department of Mental Health, CMHS participates in pencil and paper questionnaires. Although focused questionnaire would have merit, it was felt that direct contact with clients would offer the opportunity to obtain information not bounded by predetermined questions. The Quality Management unit of CMHS has also found that completing these questionnaires is burdensome to many clients. There is also evidence that standardized tools do not provide the variance that one hopes to achieve in measuring satisfaction.

A focus group or series of focus groups would have also been a viable alternative to a standardized questionnaire. There were also concerns that a focus group with more seriously and persistently mentally ill individuals might threaten confidentiality. We were not able to locate any evidence in the literature that supported the merits of a focus group. At this point, there is no way of assessing with certainty that a focus group may have been superior to individual interviews. However there is evidence in the way of participant enthusiasm and expression of appreciation that individual interviews provided each participant with the necessary acknowledgement that their specific input was valued and therefore freely and productively provided. To that end a semi-structured client interview protocol (see appendix E) was developed. The interview protocol was developed and modified after a number of drafts. The protocol posed both open and closed ended questions. Participants were surveyed on what they found helpful and not helpful, their attitudes about what they felt the system should help them with and whether they received the help they thought they should receive.

A convenience sample was drawn from the 128 clients, 1997 and 1998 community discharges. The interview sample represented all demographic categories, selected index discharge institutions, a wide range of community discharge programs, recidivist and non-recidivist clients. A number of institutionalized clients from specific outlying institutions were eliminated due to geographic distance. The table on the next page provides the specific breakout of interviewee characteristics. With the aid of a translator, three clients were interviewed in their native Chinese language. Clients were recruited from the sample with assistance from the current provider of service. A $20.00 stipend was provided for all participants. Participants were required to be able to cooperate with the interview, to be relatively verbal and not floridly psychotic during the interview. Participants were required to sign a consent to participate (see appendix C). The authors relied upon participants' care managers' assessment of the clients' conformity with the interview criteria. The interview protocol was piloted on four clients. The pilot enabled final modifications of the tool. The interviews were conducted by a clinical psychology student and experienced interviewer from the Saybrook institute. Participants were interviewed in program

offices, institutional settings and CMHS administrative offices. Each of the interviews was taped and transcribed. Transcription themes were abstracted and categorized by study authors and interviewer.

The CMHS BIS was used to determine demographic participant information. Of attempted recruits, 13 clients did not participate in the interview. The client's care manager deemed four of these clients inappropriate for an interview. The interviewer eliminated one client after the client was found to be psychotic. One care manager did not respond to repeated requests for assistance in locating three recruits. Five clients refused to be interviewed. One of the refusals left the interview before completion; this occurred during the pilot phase.

L-Facility Discharged Interview Sample

	Interviewed	Not Interviewed
Institution		
MHRF	23	54
Canyon Manor	4	19
Crestwood Vallejo	2	17
Gender		
Male	15	53
Female	14	48
Race		
Caucasian	13	57
African American	9	24
Latino	3	3
Asian/Pacific Islander	4	9
Age		
21 – 30 year olds	1	8
31 – 40 year olds	8	11
41 – 50 year olds	5	30
51 – 60 year olds	9	21
61 – 70 year olds	4	16
71 and older	2	15
Diagnosis		
Schizophrenia (excluding schizoaffective)	7	36
Schizoaffective	16	38
Mood disorders	6	17
Recidivist Status		
Recidivists	2	19
Non-Recidivists	27	82

Note that some institutions and diagnoses were <u>not</u> included in the above table. Note that further verification of recidivist demographics may be necessary.

<u>Findings</u>

The results of the transcriptions were initially catalogued in the following manner:

1. Open ended questions, which asked interviewees as to what was, and was not helpful.
2. Open ended question as to the types of problems which interviewees perceived that the mental health system SHOULD provide assistance.
3. Direct questions that queried interviewees as to whether the mental health system did provide assistance with various needs, e.g., primary care, substance abuse, housing, activities of daily living, vocational preparation, relationship problems and medication?
4. Questions as to what sources of support they received outside of the mental health system such as, family, friends, religion, alcohol, drugs, cigarettes and recreational activities?
5. Direct questions as to whether interviewees preferred the community to the institution and whether they felt prepared by the institution to live in the community.

The results of these categories have been categorized in the following specific areas. These issues are also considered in the concluding discussion section.

Social Contact and Interpersonal Relations

Issues surrounding social contact were perhaps the most significant result from the interviews. Facets of this issue arose in a variety of contexts within the interviews. Participants expressed appreciation for the social and interactional aspects of care, such as: being around people, feeling cared for, feeling

understood and wanted emotional containment and consistency in providers. Conversely, some participants expressed dissatisfaction with lack of staff time, inconsistency in providers, lack of interpersonal skills on the part of providers and being locked up for too long.

Most participants did not express a need for help with relationships, that is that they did not identify that they were having problems with relationships. Perhaps more salient is the fact that few participants had any experience with intimate relationships. A significant majority declared that they were unable to identify any "good friends." There were a number of instances in reports from participants where they indicated a need to have social activities and contacts arranged or a desire to receive guidance in how to make contact with others.

Relationship with family was divided. Many expressed appreciation for the help and support they received from their family. At least a third declared that they received no help from their family

Case Management
Regarding how the mental health system could help, practical day to day concerns was the most frequent mention. Participants expressed appreciation for case management and the practical assistance that case management enabled. A number of participants made mention of their case manager, noting that they were particularly helpful with fulfilling various practical needs.

Medical Problems
Those who needed help with medical problems expressed that they received that help. About 40% of participants indicated that they did not need help with physical health problems. It should also be noted that there might be some confusion in the role of psychiatric and medical services.

Activities of Daily Living
It is notable that the overwhelming majority of participants failed to acknowledge the need for assistance with ADLs. It is obvious to most providers that individuals, especially during an acute phase of an illness, would clearly need help with this area of day to day functioning. Given that a number of participants were able to identify that others needed help, it would appear this is one area where individuals lack insight into their own needs and/or that this area is so fundamental to personal competence that any admission of need would be far too shameful to confront.

Transportation
Participants expressed consistent satisfaction with transportation arrangements.

Housing
Board and care homes received the strongest endorsement for their location, cleanliness and provision of a wide variety of services. This endorsement was made by some as a decided preference over hotels. A number of factors suggest that board and care homes facilitate community tenure because they have a home like setting, they are in residential communities as opposed to more commercial or more obvious marginalized areas of the city. The people who operate the homes pay closer and more personal attention to the clients.

Vocational Preparation and Structured Activities
Many more than half of the participants expressed satisfaction with the mental health system's provision of opportunities for **vocational** preparation or other forms for daily structure, e.g., day treatment. This sentiment was echoed in various ways in many individuals' need to have daily routine, a place to go, a feeling of being useful. A few participants also indicated that they were not ready for work. While some expressed appreciation for structure including day treatment programs, others complained that they felt demeaned by the rote and cliched activities that were available in day treatment programs.

It was noted that vocational preparation and daily structure were not age dependent. Indeed, many older participants were eager to be engaged and to make productive use of their time.

More than half of the participants report that they did not have nor were they able to engage in **recreational** activities. It was not clear whether this "inability" results from lack of opportunity to access

recreational activities or whether illness itself contributed to a loss in interest in relying upon recreation for its pleasurable benefits.

Medications
Medications were an important issue for participants. Many participants acknowledged how medications have helped and not helped. Many participants indicated that they were more satisfied with the medication that they were currently receiving then medications in the past. This could be attributed to the imperfect and laborious pathway to finding the right medication regimen and /or to the possibility that medications themselves have improved. A number of participants expressed frustration with the titration process of achieving therapeutic objectives. Sedation or being "over medicated" seemed to be the most bothersome side effect. A good number of participants complained about their providers' inability to hear or respond to their complaints

Religious Activity
A least half of the participants acknowledged and expressed benefit from religious or spiritual belief. This raised the question as to whether providers pay attention to religious desires in facilitating the individual's recovery. Conversely, at least a third of the participants eschewed the idea of religion.

Substance Use and Abuse
Most participants denied that they needed help with substance abuse problems. A significant minority of participants indicated that they felt a need and did receive help with their substance abuse. 12 step programs were specifically mentioned as helpful. Some participants acknowledged that being in the L-facility provided them with an opportunity to address their substance abuse problems. A few participants expressed that the approach to substance abuse intervention, e.g., relapse and the requirement for abstinence, was too rigid.

Some acknowledged that they actually appreciated the benefits of drug and alcohol use although most indicated that they understood the deleterious effects. The one exception was cigarettes where the majority of participants had a very strong affinity for smoking. In contrast to other drugs, there was very a strong endorsement for the benefits of smoking. A number suggested that smoking was very helpful.

Discussion

A few caveats should be acknowledged about methodology and especially about potential selection biases. The interview requirements and the care manager facilitated selection process may have biased the sample. Upon review of recidivism status, the authors made a number of attempts to increase the interview pool with earlier recidivists. These efforts resulted in a 10% participation by early recidivists. It is notable that we found no appreciable difference in participant response when recidivist and non-recidivist transcripts were reviewed. Upon review, the authors and interviewer questioned the quality of the results of the translator-facilitated interviews. There is some evidence that the use of a translator may have inhibited a richer report of experience within the system for these client participants. This deficit itself may mirror the system's failing to fully provide culturally appropriate service. Notably, a number of participants complained about difficulty in communicating with their providers, regardless of language. We can only assume that a language barrier may exponentially complicate the communication bridge.

What was learned from the interviews?

The findings provide significant observations about the strengths and weaknesses of the service system. Even the recidivist pool of clients demonstrated a fair amount of motivation and at least in part, expressed satisfaction with services. There are however, a number of issues that even well informed students of mental health services would benefit from considering as a result of this evaluation.

In pursuing dialogue with clients of mental health services some would question as to whether individuals with severe and persistent mental illness are able to provide useful and reliable reports on their experience of mental health services. Indeed, during the interview a number of the participants were clearly symptomatic. The fact that few clients acknowledged the need for help with basic self-care needs would indicate significant denial. The relevant questions: do such individuals have insight into their

illness and the treatment process? How important is insight? In fact, a number of clients did convey that their evolutionary acquisition of insight was a critical component of their recovery. We cannot overlook or ignore the function of insight in any recovery process. This issue is very pertinent to this population. This question is even more germane given that all individuals in this sample received treatment on an involuntary basis. Compulsory treatment is not a recipe for obtaining a high degree of affection for mental health services.

- ***In spite of the effects of the illness itself and at times apparent intractability of the illness, participants provided insightful, clear and cogent comments about their experiences in the mental health system. It is especially notable that a number of participants expressed a great deal of gratitude for having the opportunity to provide feedback.***

Community versus Institution?

The identification of what contributes to longer-term community tenure raises a number of underlying questions, such as: Is moving an individual to the community cost effective and do clients, themselves want to be in the community? The answer to the second question was overwhelming; the ***great majority was unequivocal in their endorsement of preferring the community to the institution.*** Some were also able to articulate the need for and benefit from being in the institution. Two participants expressed preference for the institution given the amount of support and attention received in those facilities. The Billing and Information services analysis provides data indicating higher acute services use for recidivist specific but cost analysis and comparison was beyond the scope of this report.

Less favorable in the results was client satisfaction with their institutional tenure. Few clients were able to acknowledge how they felt prepared to return to the community. ***In fact, a majority of participants expressed that they did not feel that the L-facility prepared them to return to the community.*** This could be explained in part to the compulsory aspect of institutional care. If we assert that the benefits of the community are mirrored in the institution, it would appear that many clients are unable to make an "objective" assessment its value. One could suggest that there is no way around obviating the adverse experience of involuntary treatment. That may be, but we also found that some participants were also able to appreciate the need for institutional care. There may be something to be learned from the one area that participants did express value and that was the "pass" privilege away from the institution.

- ***The authors of this report suggest that enhanced and increased interaction with the community, e.g., overnight passes, and more contact and presence from community providers may enhance motivation and satisfaction with institutional care. This suggestion is also complemented by input offered by providers in the focus group (provided later in this report).***

The role of insight

The individual's "ability to have insight" arose in relation to a variety of issues. Many participants denied needing help with ADLs or the need for access to medical care. On the contrary, participants were quite favorable toward cigarette smoking. It is beyond the scope of this report to ascertain the veracity of participant comments regarding ADLs and health care needs. It is plausible that participant input reflects true need. Perhaps participants did in fact obtain their health care needs, did not need help with ADLs and that there is no need for worry about cigarette smoking. But more likely not. Input provided from the staff focus group indicates that clients are often quite ignorant about their primary health care needs. This ignorance is further exacerbated by the difficulty in accessing primary care for their clients. Evidence already exists that individuals with severe and persistent mental illness are at greater risk for co-morbidity. Participant endorsement of the benefits of smoking clearly indicates that more education and increased efforts to assist individuals in reducing their risk are necessary.

- ***Some clients acknowledged a need for time to develop insight about factors that triggered re-hospitalization, particularly regarding substance abuse. Some also mentioned that they had not been able to appreciate the value of being hospitalized when it was happening. They could see that it had been helpful in some way only after returning to the community and gaining perspective over time.***

It is given that "lack of insight" is the human condition. The question then: is it possible and if so, how do providers facilitate the hastening of insight for individuals severe and co-morbid health problems? The area of substance use and in particular, tobacco use presents, as an illustration of client "denial." Are there benefits from overt and subtle educational approaches? ***Providers themselves may be in need of more education and understanding on the interaction of nicotine, medication and the biopsychosocial impact of tobacco use for persons with severe mental illness. There may be a role for nursing staff and health educators in this arena.*** The larger system has already adopted a harm reduction approach in the way of restricting smoking thereby reducing the risks of second hand smoke in institutional and residential care. ***Perhaps a deliberate harm reduction/use reduction as opposed to smoking cessation approach might also be more actively considered and encouraged within CMHS educational efforts.***

The benefits of social contact and social support

As indicated above, the social aspects of care were very important to participants. This finding manifested in the following ways:

- Having the opportunity for social contact,
- The fact that few report having close friends,
- The request to have social structure,
- Attending AA meetings for the social contact.
- Living in a board and care home and being around people

Perhaps this finding states the obvious. But the fact that this issue arose in so many areas of the interview suggests that community mental health services should consider how to better harness its resources to facilitate social support. Clearly there is a wealth of literature that underscores the benefits of social support in both physical and mental health.

The interpersonal role in Case Management and Medication Services

In spite of newer technologies and continuing attempts to improve the service system, there is little doubt that the foundation of good care remains in the system's ability to foster **social connectedness** both in the relationship between provider and client as well as among clients themselves. Participants indicated a high premium for the interpersonal aspects of care in the way of:

- Having the experience of being cared for,
- Having someone to talk to,
- Having someone to provide input and constructive criticism,
- Being disappointed in providers who lack rapport,
- Feeling frustrated in not having more contact with providers,
- Appreciating the benefits of a "good" case manager who provided very concrete assistance with practical needs.

Improved "technology" in the way of access to the newer medications, appears to be appreciated by interview participants. But it also appears that in light of continuing imperfections, clients' frustration and tolerance for those imperfections may be reduced by the ability of providers to hear and respond to those frustrations.

- ***Given the paucity of "doctor time" the system may benefit considering active and deliberate utilization of other providers, e.g., nurses and pharmacists, to be seen as bona fide educators and medication service providers***

Having something to do

Perhaps a close companion to the social aspects of care is the need for individuals to feel useful, to have purpose and direction in the course of their day to day activities. In addition to the questions directly posed about vocation and vocational preparation, many participants indicated that they appreciated and benefited from having a structure, having a place to go, and having meaningful social interactions and functions. A number of individuals also acknowledged that they were not interested or ready for vocational activity.

- ***This again, underscores the need to provide alternatives, to assess readiness and to continue to actively pursue how individuals in our system can benefit from structured and meaningful activities.***

In Conclusion

Perhaps the most succinct yet humane summary of the work accomplished by this approach to the L facility outcome evaluation is found in the words of Shelley Diamond, M.A., doctoral student from the Saybrook Institute who interviewed 28 of the 29 participants.

"I was genuinely engaged with the participants in the interviews, listened attentively while transcribing the tapes, and have been mulling over the data for more than a year now. My subjective impression is that the most basic elements for maintaining community tenure appear to be: decent housing, medication that works, at least one good caring relationship, and some type of productive activity. Assessment of those elements before institutional discharge might be useful in preventing re-hospitalization. My hypothesis is that at least two of those four elements need to be achieved fairly quickly after discharge, and progress eventually made on the other two elements.

More precisely, appropriate housing placement immediately after institution discharge appeared to be critical, with a need for matching client's needs and lifestyle. Hotels received all negative reports; well-run board and care homes received mostly positive reports. Ongoing close monitoring of medication effects, with enough time given to explore and resolve problems, also seemed to be critical.

There were various types of people who were appreciated for showing and caring, active interest in participants' lives and making some effort to be helpful or supportive. Examples included case managers, board and care home operators, family members, clergy, psychiatrists, and nurses. Most of the individuals had only one such caring person in their lives. Those who had not even one close relationship were clearly at a disadvantage.

Productive activities included school, a paid job, volunteer community service, recovery and therapy groups, social activities with friends, and spiritual gatherings.

There is one other point I wanted to make. While I believe that the results of data analysis categorized by content themes have external validity, the aggregated findings lack a certain human dimension. What is unique about each individual as a whole was lost in the process of data reduction. I believe all the participants possessed valuable self-knowledge and insight that would be useful in a longitudinal study about the helpfulness of services over time. I truly enjoyed doing the interviews and working on this project."

Focus Group Data

As indicated in the methodology section, we asked provider participants both open ended and targeted questions related to their perceptions of successful community tenure (See Appendix G for Focus Group Protocol). We also provided participants with the opportunity to react to preliminary findings from the BIS, chart and interview data.

The results of the focus group found that providers' concerns fell into three general areas: transition, housing, family support and physical health.

Transitions:

Providers universally agreed that transitions were difficult for the client population. They suggested that an active review of the "institution to community" transition is warranted. The need for more linkage and bridging between the institution was emphasized e.g., more frequent visits by the care manager at the institutions and trial overnight passes outside of the institution was offered as being important.

Housing:

There was no other issue that was as strongly emphasized. Providers noted the challenges of placing individuals with special needs, be they medical, social or cultural. They also noted that having a compatible and acceptable residential placement from the client's perspective makes a big difference in outcome. It is notable that there was some difference in participants as to the ultimate goal for discharged clients. Some expressed that independent living beyond board and care homes should be the gold standard. Others expressed that a good percentage of clients will continue to need a fair amount of support and supervision while remaining in the community.

Family support and involvement

A number of participants endorsed the idea that family support was very critical in residential success. Some participants perceive that families could have a negative influence and effectively sabotage community placement. It was noted that many of discharged clients had no family support. It was agreed that not only does the system not do enough to address family needs, but that providers did need help in helping providers and that in some instances felt that they were placed in between the client and family in order to achieve system objectives.

Physical Health

A number of providers emphasized health status, difficulty of placement for many clients and difficulty in access for primary care. When participants were presented with findings from client interviews, provider participants suggested that clients were often ill informed or in denial about their physical health status.

Concluding Summary and Implications for Improvement

This section is intended to highlight salient findings, to synthesize the four data inputs and to point to areas for system quality improvement. As already noted, some of the findings and concluding results are actually an indirect result of this project but are nonetheless worthy of consideration.

The main findings:

1. The identification of a discharge was a much more complex task then originally conceived. Given the ambiguity of which client was truly a "discharge," only chart-reviewed clients were included in the analysis. Upon manual review only 128 bona fide "discharged" clients (of a potential 170) were included in the sample [BIS Data].

2. The consistency of data entry and availability of archival data limited the analysis of service use analysis [BIS data].

3. 23% of the sample cohort returned to an L facility within twenty-four months. It is clear that clients are at greater risk for recidivism earlier in their community tenure. More than a third of recidivists returned within three months. Two-thirds returned within one year [BIS Data].

4. Demographic risk factors for recidivism appears to be younger age, male gender and African American ethnicity [BIS Data].

5. Recidivists' used significantly more acute services and less IMD or outpatient services. The greater number of acute services was significant. Of perhaps greater significance, was the wide difference in IMD length of stay, both pre-index and index episodes. Non-recidivists had significantly more IMD days [BIS Data].

6. The target areas for chart abstract were less accessible in the community as compared to the institutional chart. The clinical information was frequently not available in the community chart [Chart data].

7. Recidivists appear to be more impacted by physical health problems, substance abuse, psychiatric symptoms and behavioral problems. They were also less engaged in performing ADLs, less compliant with medications and less engaged in social or vocational activities [Chart Data].

8. Medication effectiveness alone does not appear to significantly improve community tenure. Poor compliance with medications however does appear to be highly associated with recidivism. Clients do endorse the benefits of medications but appear to have a reservoir of negative experiences with medications. Sedation and lack of responsivity from providers related to medications appear to be primary complaints [Chart Data].

9. Primary residence at discharge was recorded as Residential Care Facilities (RCF) for 44% of the sample. The actual recorded residence at 12 months post discharge was RCF for 32% of the sample. Only 5% of the one-year post-discharge RCF clients were recidivists. A number of residential placements with very small numbers had no recidivism. Given the larger numbers of RCF placements and the relatively low rate of recidivism, it appears RCFs may be a significant contributor to longer-term community tenure. *Also note that this data may need further verification* [Chart Data].

10. Social contact, opportunities for social contact, learning social skills, receiving care and nurturance were very important aspects of care as indicated by client interviewees. Clients are sensitive to whether they are being heard and responded to by providers [Chart Data, Interview Data].

11. Participants appear to have little to no insight about the need for Activity of Daily Living assistance [Chart data].

12. Participants appear to have limited understanding about the need for physical health care [Focus Group Data].

13. The perceived benefits from cigarette smoking appear to far outweigh the risks [Chart Data]

14. Providers identified housing, family support, intervention, and education, increased linkage with primary care and active linkage between institution and the community as critical to successful tenure [Focus Group Data].

Implications of the findings:

It is beyond the scope of this report to offer specific and extensive recommendations or prescriptions for the improvement in the quality of care for L facility discharged clients. However the findings do offer an opportunity for the system of care to further explore or address the following issues:

1. The demographic vulnerabilities for recidivism, especially African American ethnicity, warrants further consideration. The data does not offer any specific insight into the impact of demographic variables. "Age" recidivism may correlate with length of illness; a "maturational" effect may mitigate against recidivism.

2. The above findings clearly impute service utilization for its association with recidivism. Early recidivism, longer IMD tenure for non-recidivists, client endorsement of stable and supportive living arrangements, and staff experience with turbulence during transitions suggests a need for more focus in this area. As one provider noted, "transitions are always stressful." The variety of data inputs clearly underscores the need for intensive supports upon discharge from IMDs. We should also pay attention to clients' "negative" perception of institutional tenure. The question is raised as to whether greater overlap and emphatic orientation toward the community earlier in the institutional stay might enhance client "engagement" in the institutional experience. The system may consider greater enhancement of staff linkage, increases in community passes, and overlap in community placements and perhaps even overlap in staff continuity. Perhaps creative and flexible use of institutional staffing to link with the community could enhance community tenure. Perhaps the obvious question: Is it time to increase SPR capacity?

3. Direct and indirect expressions of desire for social contact and nurturance were a consistent finding in interview data. Some focus group participants also expressed the need for more and effective family intervention. The system should examine how to harness and create more social opportunities for clients. Social support literature clearly indicates improved physical and mental health outcomes for those with positive social inputs. The system has already made some gains in this area, e.g., family advocacy, socialization groups and peer support.

4. The number of issues surrounding medication warrants consideration. Client frustration with response by medication providers might be improved by empowering other disciplines e.g., pharmacists, RNs and LPTs, to enhance their roles to assist in educational strategies. Lack of medication adherence was identified as a contributor to recidivism. Again, the system is currently piloting an intensive medication focus and adherence project.

5. In a similar vein, providers expressed concern about the lack of primary care linkage. Could Nurses play more of a role in the following areas: primary care linkage, health education, smoking reduction and smoking cessation strategies?

6. The paucity and inconsistency of documentation raises the question as to whether more systematic documentation of all domain areas might provide flags for intervention planning and recidivist prevention.

7. Housing is probably the bane of San Francisco's CMHS challenges. It does appear that a significant number of clients do better when they are in long term, supported and general San Francisco community as opposed to single room occupancy housing.

8. Further survival analysis should provide confirmation of the above findings and a greater focus on those variables that are strong predictors of recidivism.

9. The challenges to using a billing system for evaluation and analysis were clearly evident in this project. The system is currently considering a significant upgrade and re-organization of its information systems and will hopefully be better suited to provide data for quality improvement, research and evaluation purposes.

Appendices

Appendix A	Billing and Information System Query
Appendix B	Chart Review Data Summary
Appendix C	Consent to Participate in an Interview
Appendix D	Chart Abstract Tool
Appendix E	Chart Abstract Coding Guide
Appendix F	Interview Protocol
Appendix G	Focus Group Protocol

Appendix A

Process and Problems in accessing INSYST Service Utilization Data

The CMHS Billing and Information System (BIS) was used to obtain pre-index discharge services, 24-month post-discharge services and demographic information for clients in the L-facility study. In the process of assessing clients' service utilization, several problems were encountered in Insyst that made extracting accurate information difficult and, in some cases, impossible. Most of the problems arose when trying to assess clients' lifetime service utilization. In 1991 CMHS converted to Insyst from the previously used billing system. Despite efforts made to transfer existing data over to Insyst, not all of the data was successfully converted and, as a result, service data prior to 1991 is sparse. Although manual entry of data into Insyst began on April 22 1991, and, in theory, all services after this date should be accurate and complete, we also found errors and inconsistencies in 1992 and 1993.

In general, there appears to be very few problems in the service data after 1993. We therefore feel confident that the 24-month post-discharge service utilization data is reliable. Unfortunately, we were not able to assess clients' full service utilization history because of the problems we encountered in the BIS data.

Direct services before 1991

Both the Direct Services Table and the Episodes Table in Insyst provide service utilization data. The Direct Services Table was thought to be the best source of data because it provides the date of each service with the number of hours and minutes staff and co-staff billed for that service. Unfortunately, during the conversion to Insyst most of the direct services were lost and, as a result, very few direct services exist prior to 1991. Assessing lifetime services using data from the Direct Services Table was therefore not possible.

Episode data before 1991

The Episodes Table provides the opening and closing date of each episode and the corresponding service units. Although data from the Episode Table was more successful in the transition over to Insyst than from the Direct Services Table, not all of the episodes were successfully converted. It is likely that the episodes open at the time of the conversion were transferred into Insyst; the episodes that had already been closed were less likely to have been converted. As a result, episode data prior to 1991 is not complete.

Units of service in the Episodes Table vary by service modality

We also discovered a problem using the Episodes Table to assess services after 1991. The service units that correspond to an episode can not be translated into precise units of time for most of the service modalities. One unit of service in the Episodes Table represents different units of time depending on the service modality. A unit of service under mode 15 could be any amount of time ranging from one minute to eight hours. One unit of service under mode 10 represents either eight hours or four hours. Only under mode 5 (24-hour) does one unit of service always represents one day, or 24 hours. Service units, therefore, are not a meaningful unit of comparison for any services other than mode 5.

Units of service unequal to length of episode for Mode 5 services

Given that one unit of service under mode 5 is one day, or 24 hours, service units could be used to describe clients' lifetime mode 5 services. In the process of extracting this data, however, we that noticed several episodes had either no corresponding service units or had service units unequal to the length of the episode. This discrepancy, seen in both the Episodes Table and the Direct Services Table, contradicted the assumption that one service unit under mode 5 was equal to one day.

Further research into this issue revealed that this discrepancy was seen in almost all of the service modalities. Episodes in Acute Inpatient, Residential, Day Treatment, SPR, Crisis and IMD modalities did not have any units of service. Apparently it is not unusual for an IMD or SPR episode to have no units of service recorded. Often IMD programs only the opening and closing date of an episode. Service units are not always entered because IMD episode data is used primarily to track the location of the client. SPR episodes will have no units of service if the episode is under a Cluster SPR. Cluster Sprees are only responsible for coordinating services; they do not directly provide services. A client could therefore have an open cluster SPR episode with no units of services because all of his services are delivered under

other programs. There is not a clear explanation, however, for why there are episodes in the other modalities with no corresponding units of service.

To explore possible reasons for the discrepancies in the other service modalities, we gave Retha Pedigo, a BIS liaison at CMHS, six specific acute inpatient episodes that had no corresponding service units in either the Episodes Table or the Direct Services Table. After closely examining these episodes, she found that during July and August of 1993 there were no services recorded for anyone under RU 88127, 88128 and 88129 (SFGH), despite that many episodes were open under these programs. Tom Gross in the SFGH billing department was not aware of any event that might have contributed to this problem (i.e. glitches in the data entry system, changes in staff, etc.).

Although this analysis of these episodes pointed to the root of the discrepancy, it is not possible or practical to examine each mode 5 episode where the service units do not equal the length of the episode. Without an explanation for the discrepancies in the other modalities, the units of service could not reliably be used to describe clients' lifetime mode 5 services.

Alternatively, the length of the episode could be used to assess clients' mode 5 service history. Each day of an episode under mode 5 is one unit, or a 24-hour period. In theory, the length of the episode in days should provide an accurate and meaningful measurement of acute inpatient, residential treatment, IMD and ADU services. However, this would still only summarize clients' mode 5 service history. Furthermore, without being able to confirm the episode data against another source in Insyst, we are not completely confident that this data is reliable and accurate. For these reasons, we decided to assess only clients' service utilization after 1994 using the Direct Services Table. Relatively few problems have emerged in the service data after 1994 and services are recorded in precise time units. We believe limiting our analysis to these data will provide the most reliable and meaningful service utilization history, albeit incomplete.

Appendix B

Chart Review Data Summary All Numbers are Percentage		L-Facility Chart			Community Chart			Change from L-Facility to Community Chart	
		Not at all/ Minimal	Moderate / High	Unknown	Not at all/ Minimal	Moderate / High	Unknown	Not at all/ Minimal	Moderate / High
Physical Impact	Total	77	23		48	31	20		
	NR	75	23	1	52	29	19	-23	6
	R	80	20		37	40	23	-43	20
Physical Focus	Total	62	37	1	51	33	16		
	NR	63	36	1	53	32	15	-10	-4
	R	57	43		43	37	20	-14	-6
Substance Abuse Focus	Total	78	21	1	59	24	16		
	NR	81	18	1	62	21	16	-19	3
	R	70	30		50	33	17	-20	3
Cognitive Impairment Focus	Total	83	16	1	55	26	19		
	NR	82	17	1	58	25	16	-24	8
	R	87	13		47	27	27	-40	14
Engaged in Soc	Total	62	37	1	44	31	25		
	NR	62	37	1	41	35	24	-19	-2
	R	60	40		53	20	27	-7	-20
Engaged in ADLs	Total	32	66	2	23	34	42		
	NR	30	68	2	24	41	35	-6	-27
	R	40	60		20	13	67	-20	-47
Med Effective	Total	47	48	5	35	35	30		
	NR	45	49	6	34	39	28	-11	-10
	R	53	47		40	23	37	-13	-24
Med Compliance	Total	14	81	5	26	40	34		
	NR	10	84	5	23	46	31	13	-38
	R	27	70	3	33	20	47	6	-50
Behavioral Problems	Total				43	41	16		
	NR				46	38	16		
	R				33	50	17		
Psych Symptoms	Total				41	42	16		
	NR				47	36	17		
	R				23	63	13		
Empl & Edu Function	Total				51	28	21		
	NR				46	31	23		
	R				67	20	13		

NR = Non- Recidivist
R = Recidivist

Appendix C

CONSENT TO ACT AS A PARTICIPANT

Please read the following document carefully. If you have any questions, please contact Saumitra SenGupta, Ph.D., Research Psychologist, CMHS, 1380 Howard St., 5th Floor, San Francisco, CA 94103. Phone: (415) 255-3424, Fax: (415) 255-3567.

In signing this form I affirm that I understand the following:

Purpose: I am being asked to participate in a Quality Improvement Study undertaken by the San Francisco Community Mental Health Services (SF-CMHS). The purpose of this study is to identify ways to improve the quality of care for clients who have been discharged from long-term care facilities.

I have been selected as a possible participant because I was discharged from an L-facility during 1997-98. As a participant I will be interviewed for about an hour about the services I have received from CMHS. I understand that this interview will be tape-recorded.

Confidentiality: My name and the fact that I participated in this study will not be disclosed to anyone other than the SF-CMHS staff or designee conducting the study, and the treatment provider, if any, who has assisted in setting up this interview, unless I disclose it myself. The tapes will be erased once the interview has been transcribed.

My Rights as a Participant: I understand that my participation in this interview is completely voluntary and will in no way affect my present or future treatment from CMHS. I reserve the right to terminate this interview at any time and may choose to not answer every question.

Benefits: I will receive twenty dollars ($20) for completing this interview.

Agreements and Understandings: I have read and fully understood this document. The purpose and objectives of this study has been fully explained to me. I have had an opportunity to ask questions about this study and they have answered satisfactorily. I have received a copy of this form to keep.

_____

Participant's Signature Date

I have received $20 for participating in this interview.

_____ _____ __ ___ __ _____

Participant's Signature Date Social Security Number

I would like to receive a summary report of the findings of this study when it becomes available.

_____

Participant's Signature Date

Appendix D

Chart Abstract Tool

The following information will be abstracted from both the institutional chart upon discharge and from the primary community service chart at approximately one-year post discharge. An assessment of the following information will be made based upon a review of assessment forms, diagnosis, treatment plans and from the last six to twelve months of progress notes.

Client Name_____ Reviewer Name_____

From the Institutional chart:

1. During the institutional stay, physical health problems impacted the client's the functioning

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

2. During the institutional stay, physical health problems were a focus of care

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

3. During the institutional stay, substance abuse problems were a focus of treatment.

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

4. During the institutional stay, cognitive impairment was a significant focus of treatment?

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

5. During the institutional stay, the client was positively engaged in socializing activities and groups:

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

6. During the institutional stay, the client was actively engaged in performing his/her ADLs:

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

7a. List the client's discharge medications:

7b. In general, medications appeared to be:

a. Very effective	b. moderately effective	c. minimally effective	d. not effective	e. could not determine

7c. During the institutional stay, the client was cooperative with medications:

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

8. The client's planned discharge residence was:

a. Independent living alone	b. Independent living with others	c. board and care	d. Another non psych SNF	e. Residential treatment
f. Supported housing	g. Institution	h. Unknown		

9. The client's discharge status was:

a. Planned	b. AWOL	c. AMA

Client Name _____ Clinic_____

Reviewer Name _____

From the community service chart:

1a. During the last 12 months, physical health problems impacted the client's functioning

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

2. During the last 12 months, physical health problems were a focus of the client's care

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

3. During the last 12 months, substance abuse problems impacted the client's functioning

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

4. During the last 12 months, cognitive impairment was a significant focus of treatment?

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

5. During the last 12 months, behavioral problems impacted the client functioning

a. Very Much	b.Moderate	c. Minimal	d. not at all	e. could not determine

6. During the last 12 months, psychiatric symptoms impacted the client's functioning:

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

7. During the last 12 months, the client was positively engaged in socializing activities and groups:

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

8. During the last 12 months, the client was actively engaged in performing his/her ADLs?:

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

9. During the past 12 months of treatment, the client demonstrated ability to function in employment, vocational, educational, volunteer service or a care taking role:

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

10a. List significant CHANGES in medications twelve months post discharge:

10b. In general, medications appeared to be:

a. Very effective	b. somewhat effective	c. marginally effective	d. not effective	e. could not determine

11. During the last 12 months, the client was cooperative with medications:

a. Very much	b.Moderate	c. Minimal	d. not at all	e. could not determine

12. As of this date the client's residence is:

a. home with support	b. board and care	c. Another non psych SNF	d. Residential treatment	e.homeless
f. institutional	g. unknown			

Appendix E

Code Guide to the Chart Abstract Tool

1. *Impact of Physical Health Problems*

Not at all:	No mention at all
Minimal:	Client can essentially do tasks with minimal interference, can participate in groups
Moderate:	Some definite physical functioning impairment, cannot participate a lot of the time, decreased activity tolerance, ambulating problems
Very Much:	Little to no evidence that the client can participate in any activity

2. *Physical Health Problems as a focus of care*

Not at all:	No mention at all
Minimal:	Occasional mention of attention to health problems
Moderate:	Fairly extensive mention or intensive focus in one area
Very Much:	75% of documentation or at least daily mention of extensive activity

3. *Substance abuse as a focus of care*

Not at all:	No mention at all
Minimal:	Documentation of history, no evidence that issue is of current concern
Moderate:	Mention that it is a current concern; client is encouraged to go to groups, client is in fact attending groups
Very Much:	Frequent mention; client found using in institution or on pass

4. *Cognitive impairment as a focus of care*

Not at all:	No mention
Minimal:	Occasional mention of client being impaired
Moderate:	Frequent mention with definite indication of some impairment
Very Much::	Very frequent mention and attention; a primary problem

5. *Client is positively engaged in social activities*

Not at all:	Client refuses group, rarely goes out of room, is isolated, intrusive or anti-social
Minimal:	Some spontaneity, some mention of participation in group, not disruptive
Moderate:	Consistence attendance in groups, spontaneous and self initiated interactions with others
Very much:	Very active with others, documentation indicates that the client has many positive social skills

6. *Client is actively engaged in performing their ADLs*

Not at all:	client is essentially on total physical care
Minimal:	client requires a fair amount of prompting to complete ADLs; documentation indicates that there are some deficits in some areas
Moderate:	Occasional prompts may be necessary
Very Much:	No prompts, documentation indicates that client is totally independent and appears to have a great deal of skill in this area

7. *Medication effectiveness*

Very effective:	The MD documents effectiveness and the documentation clearly indicates that the client has made significant improvement.
Mod effective:	Documentation indicates definite improvements; meds are stable
Min effective:	Barely improved; documentation indicates many med changes with little to no benefit
Not effective:	MD notes no changes; client may in fact be deteriorating

8. *Cooperation with medication*

Very Much:	No documented indication of non-compliance or a clear and direct statement about compliance
Moderate:	No indication of history of non-compliance; documented indications of compliance while in the institution
Minimal:	Documented hx of non-compliance; some documented indication that the client is hesitant or reluctant to take meds
Not at all:	Documentation indicates refusal, checking or other indications of active resistance

Appendix F

Client Interview Protocol

Introductory Statement to the client:
Hello Mr./Ms./Mrs. _____ (name of interviewee). I'm _____ (name of interviewer). Thanks again for agreeing to participate in our study. I have a consent form for you to sign. The form essentially tells us that you are agreeing to this interview. I want to emphasize that if you are uncomfortable with any of the questions today, you will not be required to answer them. My goal is to help you feel as comfortable as possible. The interview should not take more than about 45 minutes. As we mentioned on the phone, the purpose of this interview is to help the Community Mental Health System by obtaining information and feedback from clients on their experiences with services. As we had discussed, we will be compensating you with $20.00 in cash at the end of the interview for your time and effort in assisting us with this study. Again we appreciate your helping us out with this very important study.

Do you have any questions about the interview?

Answer questions

Have client sign the form

No questions, proceed with the interview.

Great, then let's get started.

You have been a client at a variety of programs in the San Francisco Community Mental Health System. Most of our questions are designed to hear from you and to learn about what you think helped you. We also want to hear and learn about what you think and feel were not helpful.

(If the subject inquires about "what services?" the interviewer should summarize a variety of services the client may have received, e.g. outpatient, inpatient, subacute locked longer term care facilities, day treatment).

So my <u>first</u> question:

1. Some people would say that the mental health services that you have received are supposed to help you, do you think this is true?

As the subject responds to the above, the interviewer should encourage specifics. The interviewer will want to ask:

1a. What <u>has</u> or <u>has not</u> been helpful?

2. What problems or everyday situations do you think the mental health system should help you with?

After the client has generally responded to the above question, the interviewer should then focus on the following specifics:

Thanks for giving me your opinions on what you think the mental health system should help with. Next I would like to focus on a few specific areas that you MAY or may NOT have received help with. I should also say that some of these areas may NOT pertain to you.

The interview should list of the following issues. It is NOT necessary for the subject to respond to each of the following. However, the interview should take care to assure the subject has the opportunity to consider each of the following issues:

The formula for each of the following questions is<u>: Mr. So and so some people sometime need help with ABC, did you need help with ABC? If the client says "yes," ask for specifics. If the client reports that they did need help but did not get it, the interviewer may ask, "do you have any idea how they could have helped you?"</u>

2a. The specific areas for focus:
a. Physical health or medical problems?
b. Substance use problems?
c. Dressing, hygiene, managing money, preparing or acquiring meals, laundry?
d. Transportation?
e. Help you with getting and maintaining housing?
f. Work, school or daily structure or activities*?*
g. Social relations, making friends, getting along with people or <u>sexuality</u>?

3.Some people would say that medications are very important in helping people. Do you agree with this? How do you feel about medications? Have they been helpful? If so how so? Have there been problems with medications?

4. My next question: most people get help in many different ways. They might find <u>support and comfort</u> from all sorts of things. I'm interested in learning what has helped you in your life, what kind of things have helped you <u>get through day to day</u>? What kind of people, places or things help you?

After the subject has responded to the general question and based upon their answer, the interviewer should then ask about the following specifics:

4a. Now I would like to find out if you felt you got help from the following people, places or things?
• **Were you able to rely on your family for help?**
• **Were you able to rely on your friends for help?**
• **Did you rely on your clergy or religion for help?**
• **Some people feel that cigarettes, alcohol, drugs or are a help, was this true for you?**
• **Were there any special recreational activities, pastimes or hobbies or work that you felt were a source of support or comfort to you?**

5. ***Do you think it is better to be in the community or would you prefer to be in a hospital or institution?***

6. ***Do you feel that the services you received in long term care locked institutions prepared you to live in the community***

7. ***If you could design your own program what would it be like?***

8. If you were asking the questions in this interview, what questions would you ask?

9. Do you have any other or final comments to make?

Thank you for helping us out today!
4-2-01

Appendix G
Focus Group Protocol

Introduction

- Introduction of facilitators and participants: each participant should introduce self with name and organizational affiliation
- Background and overview of the evaluation; the purpose of the evaluation **HANDOUT** Purpose of today's group: why you have been invited to the group
- Format and topics to be covered: open ended input, specific focus areas and reactions to selected findings
- Ground rules/ Housekeeping /anonymity/Constructive Criticism/

Part One:

1.a. *As we indicated in the introduction, we're eager to obtain your input on what you think facilitates successful community tenure. So let's open the discussion with your perceptions of the factors that you are aware of that make for more successful and less successful community tenure.* At this point, facilitators should signal response from participants

Now that we have received your general input we would like to switch to particular areas of focus. We realize that you may have already covered and articulated some of these factors but we also want you to have the opportunity to weigh in on specific issues on the chance that they may have not initially occurred to you. In each of the following areas *(to be posted for participants to read on a board or as a handout)* we will ask you to chose those areas that in your experience and considered opinion are particularly germane to community tenure:

1.b. Provider and Resource Factors: what about the following factors having to do with the provider(s) do you think are particularly important for discharge and community tenure:

- Handout

1.c. Client Factors: what about the following indigenous client factors do you think are particularly relevant to discharge and community tenure:

- Handout

Break

Part II

During this last part, we are going to present to you some of the findings from the BIS, chart and client interviews. We're eager to get your reaction. Do these findings fit your expectations? How do they differ? If they differ, do you have any sense why?

Handout

S will summarize the BIS and chart data; K will summarize the interview data

Tell us what you think. ***The facilitators will seek general feedback but also seek to get specific response on all findings.***

Wrap Up and thank yous

Total Time

Focus Group Handouts

Evaluation Objective

- To identify factors that correlate with longer-term community tenure for L-facility discharged clients

Who was included in the evaluation sample?

- All clients for whom the Community Mental Health Services (CMHS) Billing and Information System (BIS) indicated a discharge from an L-facility during 1997 and 1998.
- Of this group, we manually inspected each face sheet (MHS 140) to ascertain that the client had in fact been discharged to the community for a period of more than 24 hours. This resulted in 128 individuals

Methodology:

The evaluation employed a combination of methods and sources of data:

- BIS: provides demographic, discharge diagnosis and 12 month post-discharge service utilization
- Chart review: we looked at the following factors for up to one year before discharge from the L-facility chart and at the community program chart for up to one year post-discharge: impact of physical health problems, focus of care for physical health problems, substance abuse, cognitive impairment, engagement in social activities, engagement in ADLs, medication effectiveness, medication cooperation, behavioral problems, psychiatric symptoms, vocational functioning
- Client Interview: we conducted semi-structured interviews using both open and close ended questions to ascertain feedback on the client perception of services from 27 participants
- Staff Focus group: this is today's meeting with both institutional and community providers to obtain your perception and understanding of what contributes to longer and more successful community tenure

Results

BIS

- 15.6% or 20 of the 128 clients **returned to an L-facility within twelve months**. 9 of the 20 clients returned within 3 months
- Within this group, there was **no** specific demographic (age, race or gender) or diagnostic group that appears to be at greater risk than others for returning to the L-facility.
- **Non-recidivists** clients, those who remained out of the L-facility for more than 12 months **used significantly more** ACT, Residential treatment, Acute diversion programs and Day treatment programs than recidivists clients who returned to the L-facility within 12 months
- **Recidivists** clients **used significantly more** acute and crisis services. In fact, the recidivist group had over three times the amount of hospital days when compared to the non-recidivists.
- It was also noted that clients who went AWOL or AMA had an equal chance of returning to an L facility within 12 months as those who left the L-facility in a more conventional discharge.

Chart Data

- Institutional chart: recidivists did NOT appear to have greater focus or impact in: physical health problems, substance abuse or cognitive impairment. But they did appear to be less engaged in

performing ADLs, medications were minimally effective or not effective and they were minimally or not cooperative with taking their medications

- Community chart: recidivists did NOT appear to have greater focus or impact in: physical health, substance abuse or cognitive impairment. But then did appear to have greater behavioral problems, psychiatric symptoms, were less engaged in performing ADLs, were very much less engaged in socializing activities or vocational pursuits, their medication was minimally or not effective and they were minimally or not cooperative with medication
- Primary residence at discharge was recorded as RCF for 44% of the sample. The actual recorded residence at 12 months post discharge was RCF for 32% of the sample. Only 5% of the one-year post-discharge RCF clients were recidivists. Although this was not the best, some residential placements with very small numbers had no recidivism, it appears that Refs may be a contributor to longer term community tenure.
- 11% of non-SPR and 20% of SPR clients were early recidivists

Interview Data

General

- In spite of long histories of severe and chronic mental illnesses, participants provided insightful, clear and cogent comments about their experiences in the mental health system.
- The great majority was unequivocal in their endorsement of being in the community over the institution. Some were also able to articulate the need for and benefit from being in the institution. Two participants expressed preference for the institution given the amount of support and attention received in those facilities.

Social Related issues:

- Expressed appreciation for the social and interactional aspects of care, e.g., being around people, feeling cared for, feeling understood and wanted, emotional containment, consistency in providers
- Conversely, participants expressed dissatisfaction with lack of staff time, inconsistency in providers, lack of interpersonal skills on the part of providers, being locked up for too long
- Most participants did not express a need for help with relationships. This may due in part by to the fact that few participants have much experience with intimate relationships. There were a number of instances in reports from participants where they indicated a need to have social activities and contacts arranged or for help with how to make contact with others.
- Relationship with family was divided. Much expressed appreciation for the help and support they received from their family. At least a third declared that they received no help from their family
- A significant majority was not able to identify any "good friends."

Case Management

- As regards how the mental health system could help, practical day to day concerns was the most frequent mention.
- Expressed appreciation for case management and their practical assistance that case management enabled

Specific Issues:

- Those who needed help with **medical problems** received that help. About 40% of participants expressed that they did not need help with medical. It was also noted that there may be some confusion in the role of psychiatric and medical services
- It was notable that the overwhelming majority of participants failed to acknowledge the need for assistance with **ADLs**. We questioned whether this activity was considered so fundamental to personal competence that any admission of need would be far too shameful to confront.
- Participants seemed satisfied with **transportation**
- **Board and care homes** received the strongest endorsement for their location, cleanliness and provision of a wide variety of services.
- Many more than half of the participants expressed a desire and / or satisfaction with the mental health system's provision of opportunities for **vocational** preparation or other forms for daily structure. A few participants indicated that they were not ready for work. More than half of the participants report that they did not have nor were they able to engage in **recreational** activities.

- **Medications** were an important issue for participants. Many participants acknowledged how medications have helped. Many also differentiated what meds were and were not helpful. Sedation or being "over medicated" seemed to be the most bothersome side effect. A good number of participants complained about their providers' inability to hear or respond to their complaints
- A least half of the participants acknowledged and expressed benefit from **religious** or spiritual belief

Substance Abuse:

- Most participants did not feel that they needed help with substance abuse problems. A strong minority of participants however did feel that they needed and did receive help with their substance abuse. 12 step programs were specifically mentioned as helpful. A few participants expressed that the approach to substance abuse intervention, e.g., relapse and the requirement for abstinence, was too rigid.
- Some acknowledged that they actually appreciated the benefits of drug and alcohol use although most indicated that they appreciated the deleterious effects. The one exception was cigarettes where the majority of participants had a very strong affinity for smoking

Provider Factors

- **Preparation by the institutional facility**
- **Medications**
- **Housing**
- **Specific community modalities, e.g., intensive case management**
- **Transportation**
- **Vocational Rehabilitation**
- **Skills Training**
- **Practical supports**
- **Entitlements**
- **Miscellaneous**

Client Factors

- **Health Problems**
- **Substance abuse**
- **Cognitive functioning, e.g., dementia**
- **Behavioral problems**
- **Psychiatric symptoms**
- **Special circumstances, e.g.,, fire setting, sexual predators, incontinence, disability**
- **Demographic factors, e.g., age, gender, race, sexual orientation**
- **Historical service utilization patterns**
- **Medication Adherencep**