

## **Four-year outcome report**

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## Outcome for Patients Four-Years after Hospital Closure

For the past half century, the goals of mental health treatment have been to provide people with serious psychiatric disabilities effective treatments in the least restrictive settings. As capacity and expertise for community psychosocial and psychiatric services have evolved, most people with even the most serious psychiatric disorders receive nearly all their treatment outside of hospitals. During the first decades of the shift to community services, a majority of people with psychiatric disorders were accommodated, with varying degrees of success, and length of hospital stays decreased substantially (Desai & Rosenheck, 2003). However, those with complicated clinical needs and few social and family resources, and those with substance abuse problems and sexual and criminal offenses, experienced long stays in hospitals as their primary mode of treatment (Fisher et al 2009).

In 2007, Mayview State Hospital was one of eight psychiatric inpatient facilities managed by the Commonwealth's Department of Public Welfare. Mayview State Hospital was closed in December, 2008. Mayview (then called Marshalsea) opened in 1893, and operated as an asylum and poor house until 1941, when it came under state management. In the 1930's, the time of the highest census, Mayview was home to over 4,000 residents. The census has been declining since the discovery of more effective psychotropic medications in the 1950's, and the advent of community-based mental health services and deinstitutionalization in the 1960's. Mayview served as the state-operated long-stay psychiatric facility, and forensic unit, for five counties in western Pennsylvania, including Allegheny, an urban county that includes the city of Pittsburgh, and four rural or semi-rural counties, including Beaver, Greene, Lawrence and Washington counties. Plans to close the hospital were announced in August, 2007.

In anticipation of the closure of Mayview State Hospital, the five surrounding counties collaborated on reviewing and strengthening the portfolios of community-based services and housing options. The planning group included representation from state and local mental health officials, providers, consumers, families, managed care, advocates, each county, and the hospital. A process was established to develop a Community Support Plan (CSP) for each individual discharged. CSPs were developed over multiple planning sessions, and included family members, providers, and advocates of the individual's choosing. This paper reports on a four-year, prospective, multi-method, longitudinal study of outcomes for people discharged. The design and content of the study incorporate the perspectives and findings of the comparable cumulative research, discussed below.

### Background

In the past two decades, long stay patients have been relocated or re-settled as many public psychiatric hospitals have closed. Their short- and long-term adjustments are reported consistently as mostly positive in clinical, social, and service delivery domains in the US as well as other countries (McIerney et al., 2010, Ireland; Furlan et al., 2009, Italy; McCrone et al., 2006, UK; Nierman & Lyons, 2001, US; Okin et al., 1995, US; Rothbard, & Kuno, 2000, US)<sup>1</sup>. Rothbard and Kuno (2000) examined the outcomes of hospital closures in Philadelphia, Massachusetts, London, and Italy and concluded, "the long-stay

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<sup>1</sup> Throughout the report, we use research terminology that may differ from policy and advocacy language.

discharge population shows an improved life satisfaction following discharge, with little or no deterioration in level of functioning. In addition, costs have generally been the same or less for discharged patients living in the community. In Philadelphia, the cost of care was substantially reduced; in Massachusetts, as well as London, costs were, on average, no higher in the community versus the state hospital, particularly after the first year following discharge.” Mclerney et al. (2010) report that five years after discharge the gains of the first year were not sustained. However, Okin et al. (1995) found that at 7.5 years, overall well being and functioning were stable if not improved, and McGrew et al (1999) had similar results in their followup of patients discharged from a closing hospital. It will be important to continue longer term follow up studies to explore which improvements endure and progress, and which deserve ongoing or increased attention.

Topor and colleagues (2009) and Flanagan and Davidson (2009) point out that recovery and resettlement from hospital to community are long term processes, and that developing social relationships and dealing with stigma are enduring challenges. In a consumer-led research project, McCourt (2000) found that four years after returning to community living, the respondents preferred the freedom and comfort of their living situations, and that attaining autonomy in decision making and exercising individual advocacy were important unmet goals.

Along with the generally encouraging results of relocation, it also clear that it is much more complicated to provide excellent care for the former long term hospital residents in a wide range of community settings than it is to confine people with serious disabilities in self-contained institutions. For all of the recognized shortcomings of hospital care, long term placement provided food, shelter, on site psychiatric and medical care, and protection for many patients. A community system must also address many of the same clinical and daily living needs, many of which cross the boundaries of social and psychiatric service systems. The current mental health care system should be versatile enough to serve the former hospital residents along with others with mental health needs – that is, complex, flexible care must be available on a routine basis.

A collaborative process was used to close Mayview. Stakeholders from local and state mental health systems and family and consumer advocates participated in the planning, implementation, and assessment of outcomes, meeting monthly and then quarterly over four years. The researchers for the study reported here participated in this process for the duration of the study. Community services over a five-county region that would be affected by the hospital closing were developed and enhanced first. A three-year community planning process focused on the development of housing and services, and a Community Support Planning (CSP) process was developed to create individualized discharge plans for each resident of the hospital. Individualized planning included the resident, advocates and family members of the resident’s choosing, and mental health professionals. The planning process could take from one to six weeks. This document followed the people who were discharged, becoming the benchmark against which community services were assessed and patients’ progress measured.

## METHODS

### *Overview*

The study followed a random sample of people living in the hospital who participated in the CSP discharge planning process. Participants were recruited separately for the first two years of the study (Phase 1) and the final two years of the study (Phase 2), described in detail below. 92 of 121 people approached (76%) participated in at least one time point. Interviewers met with participants every three months over the four year study period, and about two thirds of active participants completed each observation.

Procedures included standardized assessments and qualitative observations. Standardized assessments were completed every six months (in the hospital, at 6 months, and every six months thereafter until 48 months post-discharge). Qualitative observations were the focus of assessment at each of the intervening time points (at 3 months, 9 months, and every six months until 45 months post-discharge). Field notes were taken at every visit. In addition, two lengthier interviews were conducted. The first of these sought participants' views of their experiences with the relocation procedure, and the second focused on their sense of "home" and satisfaction with their living arrangements. Assessments were conducted in participants' homes.

All study interviewers were graduate students at the University of Pittsburgh School of Social Work or Public Health. Study personnel also included two senior faculty from the University of Pittsburgh (KG) and the University of North Carolina, Chapel Hill (SE), and an experienced project director (CK). Study interviewers received 10-20 hours of training on the study procedures from the project director. Training particularly focused on two instruments that required interviewer ratings, the Brief Psychiatric Rating Scale, and the Social Adjustment Scale-II. All staff were supervised by the project director and the senior faculty at weekly staff meetings. At these meetings, study procedures were reviewed, and each interviewer's contacts with each participant were discussed.

All procedures were approved by the University of Pittsburgh Institutional Review Board, and participants were reminded at each assessment that they were free to decline any part, or all, of the study participation, and their decision about whether or not to participate in no way affected their services.

### *Sample*

Participants were recruited from two random samples. Six months before the closing, we approached a random sample of 89 individuals, 65 (73%) of whom consented to participate. Two years after the closing we re-approached the original sample, and added a second random sample of 32 people. Of the original sample of 89 individuals, two people had died, and 2 were incarcerated and could not be contacted. Fifty-one participants re-consented and 7 decliners joined the study. Twenty people from the new sample of 32 consented.

The overall participation rate across the two samples was 92 of 121 individuals (76%), with 65 people participating in the first two-year period, and 78 people participating in the second two-year period.

### *Recruiting and Retention*

We were assisted by county staff and providers to approach individuals regarding their willingness to participate in the study. After being given permission to contact potential participants, we explained the procedures, and assured people that that they could skip any part of the procedures they did not like and that their participation in no way affected their services. People could join the study at any time during the study period, with some people joining as late as 18 months into the two study periods (Phase 1 and Phase 2). Separate consent was sought for the two phases of the study. Consent forms were signed when the participant agreed for both phases. At each visit participants were reminded that they could participate or not, that they could skip any part of the procedure they did not like, and also that they could withdraw participation. Participants' ability and willingness to engage in the study fluctuated over time. At each time point we attempted to make contact with each participant, often multiple times. A few participants were unable to complete standardized assessments but willing to participate in the study, for these people interviewers engaged in a conversational process and completed field notes to record important information.

Table 1 shows the number of observations by time point, and Table 2 shows the number of standardized time points completed by each participant.

Table 1. Sample sizes for study phases

<i>Period of participation</i>	<i>N</i>
Years 1-4	51
Years 1-2 only (Phase 1)	14
Years 3-4 only (Phase 2)	27
Total	92

Table 2: Number of observations by time point (number of participants in the study = 92)

Phase 1				Phase 2				
Hospital	6 mo	12 mo	18 mo	24 mo	30 mo	36 mo	42 mo	48 mo
<b>19</b>	<b>41</b>	<b>50</b>	<b>51</b>	<b>60</b>	<b>55</b>	<b>62</b>	<b>66</b>	<b>58</b>

In addition to those tabulated, 20 standardized assessments were conducted at the check-in time points, for people unable to participate at the usual time. Throughout this document, means are estimated using the standardized assessments completed on schedule at the major assessment times; however, the analytic technique used takes advantage of all data.

We estimate that during the four-year study period we made about 1000 visits to participants' homes. During this time, 482 standardized assessments and 357 check-ins were completed for the 92 participants.

Table 3: Number of standardized assessment completed for all participants

Number of standardized observations	Frequency	Percent
1	6	6.5%
2	10	11%
3	6	6.5%
4	18	20%
5 or more	52	56%
Total	92	100%

### *Measurement*

We used a combination of qualitative and quantitative techniques to learn how participants were faring in the community settings to which they were discharged.

#### *Interview and Observation Data*

There were three qualitative data collection techniques.

*Check-in visits.* About three months after each standardized assessment interviewers “checked-in” with participants. Visits were casual and conversational; conversations were guided by a semi-structured interview designed to learn how the participant was feeling about their services and living situation. Interviewers also talked with providers, and took field notes.

*Field notes.* Interviewers recorded field notes at every standardized and check-in visit. Field notes included the interviewer’s observations of the participants' well being, information from staff at group living facilities, and direct quotes from conversation with the participant outside of the interview format.

*Extended interviews.* We asked each individual to participate in two lengthier interviews to learn in more depth about their experiences. The first interview, which was conducted in the first 18 months of the study period, addressed participants’ experiences with the hospital closing process and their relocation. The second interview, conducted in the last 18 months of the study period, addressed their experiences of their new homes. Forty-one people participated in the first and 32 people participated in the second interview.

### Standardized measures

We conducted standardized assessments using research-validated instruments that measured psychiatric symptoms, social adjustment, attitudes towards medication, quality of life, progress towards recovery, and perceptions of care. Most standardized assessments were conducted as interviews, in which questions were read to participants, and their answers noted. The Brief Psychiatric Rating Scale and the Social Adjustment Scale are ratings made by interviewers after observations and standard probes. We offered shortened versions of most questionnaires to participants if they became fatigued or agitated, but wished to continue. We frequently made multiple visits to the participant's residence to complete as much of the assessment as they wished. We also ranked the restrictiveness of living situations in order to assess whether living situations became less restrictive over time.

### *Analyses*

#### *Interview and Observation Data*

These data consisted of the transcripts of the semi-structured and conversational interviews, transcripts of the relocation interviews, and interviewer field notes. The authors read all of the qualitative material in order to develop a summary trajectory for each participant, and to identify and refine common themes and outlying experiences. Next a modified type of targeted content analysis was undertaken to determine the distribution and variations of the identified themes across the sample and by participant over time. We regularly discussed all qualitative materials and their summary over the course of the study, in an iterative process of conceptual mapping and themes development.

#### *Standardized Measures*

Change over time was analyzed with latent growth curve analyses. These are specifically designed to estimate change over time in studies in which observations are missing and participants join at different points in the study trajectory, as was the case here. The analysis estimates a rate of change for each individual based on the data available for that person, and uses those estimates to calculate a rate of change for the group. That rate of change is then tested for statistical significance. An individual's rate of change can be estimated from any two observations; thus, the analysis is well suited to data sets with missing observations. Analyses were conducted using SAS 9.2, PROC MIXED and PROC GLIMMIX. These procedures are especially useful given that participants were recruited in two waves, as each person's data can be used to estimate their trajectory as long as they contributed at least two observations.

Where they are available, we also provide means from other published samples in order to provide perspective on how people discharged from Mayview fared compared to other similar groups that have been studied.

## **RESULTS**

### Sample characteristics

Participant characteristics are shown below.

Table 4. Sample characteristics

	Range or category	Average or Percent
Age	19 to 90	46.2 years
Gender	Men	63 (68%)
	Women	29 (32%)
Race	White	52 (57%)
	African American	40 (43%)
Race/Gender	African American Men	28 (30%)
	White Men	25 (38%)
	African American Women	12 (13%)
	White Women	17 (19%)
Length of Mayview residency	5 months – 22 years	4.3 years
Length of residency (frequency)	< 1 year	11 (12%)
	1-2 years	29 (32%)
	2-5 years	26 (28%)
	5-10 years	14 (15%)
	> 10 years	12 (13%)
Primary diagnosis	Schizoaffective Disorder	36 (40%)
	Schizophrenia or Psychosis NOS	43 (48%)
	Major Depressive or Mood Disorder	5 (6%)
	Other (Bipolar, Impulse Control, Personality)	5 (6%)

#### *Death and incarceration*

Nine people died over the four years of the study. One person died in an incident resulting from a violent episode related to his mental health disorder. The others died of various illnesses. Age at death ranged from 41-92, the median age at death was 59. This pattern is indicative of the serious physical illnesses and sometimes fragile health of people with serious mental disorders.

Four people experienced periods of incarceration long enough to affect their study participation. One of these periods of incarceration related to a violent felony. Other episodes of incarceration related to substance possession or use or property crimes.

#### *Interview and Observation Results*

##### *Summary of Phase 1 results*

At the two year post-discharge mark, interview and observation data showed that participants decidedly prefer their new residences to Mayview, that they felt mostly safe and comfortable in their current residences, and that progress on community integration remained challenging.



*Participants prefer their new residences to the hospital*

Participants conveyed repeatedly that they overwhelmingly prefer their new residences to the hospital. Almost to a person they stated that they preferred their new residence because they had more freedom. They also stated that they preferred living in smaller settings in which they had more say over the day-to-day aspects of their lives, including when and where to go out, their room décor, and choice of music and television programming and other activities. In almost every instance, participants also preferred the food quality and type in their current residences, and had similar irritations with the house rules about smoking as they had at the hospital.

*Interviewer prompt:* Compare where you are now to Mayview.

*Participant Responses:*

No comparison. It's better. It's the freedom factor.

I have more freedom. I like the staff here. I like the fact that I can do my own laundry.

I'm free. I go more places. I do what I want to do.

*Community integration is difficult, and life can be monotonous*

A substantial minority of participants reported that their lives were rather static. Some people reported that there were few choices of activities, while others found the rounds of occasional outings to the same settings monotonous after some period of time.

*Interviewer Prompt:* What is a typical day like here now?

*Participant:* Sleeping. [Laughs.] *Interviewer:* You just sleep all day? *Participant:* No. I get up and watch TV or come out here and smoke. *Interviewer:* What else do you do during the day? *Participant:* Nothing.

Although reports of a substantial minority of participants suggest that more variety in activities, and more stimulating activities would be welcome, some people are well integrated into community activities.

*Participants depend on staff*

In keeping with the difficulties of community integration, a substantial number of participants rely primarily on staff for social contacts, and often see few people other than residential staff or service provider. As stated by one participant: "no one has visited me besides my peer mentor and CTT." Some people reported these contacts to be very positive, though not all.

### Positive assessments

[CTT is] not bad. I like them guys. They're nice. They do things for you—take you out shopping, get something to eat. They're always busy when they come here. They have to go somewhere, be somewhere. They got a bunch of clients. Their caseload is too high.

I have 24-hour access to my case manager. I can call her whenever I need help or need to talk. She is my best friend, guardian, and big sister.

### Critical assessments

I have no idea how long I'm staying here or where I'm going or nothing.

They were promising a complete wrap-around thing, and what I ended up with was not a wrap-around thing.

Yeah, the staff makes me nervous. I don't know why.

### *Summary of Phase II results*

Phase II qualitative interviews focused on issues that were illuminated during the analysis of Phase I data. Phase I participants noted that they had limited social activities and would welcome more visitors and more varied schedules. Service satisfaction data from Phase I also indicated that, though participants rated their caregivers highly, they expressed their displeasure with them in qualitative interviews. Finally, Phase II interviews explored participants' feelings about their new homes and their perceptions of what makes a residence feel like home to them.

Interviewers asked study participants to describe a typical day. Many participants described solitary activities, such as watching television, listening to music, and playing video games. A number of individuals described sleeping and smoking cigarettes as major daily activities. Moreover, the majority of participants nominated staff and caregivers as the people they see most often and with whom they have the most contact. Participants offered mixed responses when interviewers inquired about activities that they would like to pursue. While some participants appear satisfied with their level of activity, others are looking for more options but require additional guidance to explore their options and to get started. One participant stated that she experiences difficulty "thinking of something and following through with it." Another participant, when discussing the typical activities organized by staff at his residence, like movie and game nights, mentioned that he would like to participate in activities that are more "mature," such as dating. Outings continue to be a significant leisure activity for participants. They look forward to the times that staff or CTT take them out to run errands or on special outings, such as baseball games and amusement parks.

Participants give mixed reports about staff and services. The majority of participants describe staff as "pretty good" and available when they need them. Another participant noted, "They treated me very fair...They're hospitable to me." However, disagreements with staff are not unusual. One participant

mentioned that his treatment providers aren't "cooperating." Another individual stated that some of the staff at his LTSR were giving him "double talk." Similar to their thoughts about leisure activities, participants were uncertain about the ways in which services could improve. A few participants noted that they rely on staff to provide them with feedback about how well they are doing. One woman told her interviewer that she did not feel that she could judge on her own whether or not her symptoms were improving. Another individual said that he would not know if his life were improving unless he took a step back to examine it. These individuals use observations from staff to aid them in forming their perceptions about changes in their mental health.

The majority of the time spent during the Phase II interviews focused on the meaning of "home." Since Phase I interviews explored participants' experiences with leaving the hospital and moving into new homes, Phase II interviews continued the trajectory and discussed participants' feeling about their new homes and their perceptions of what makes a place feel like home to them. Overwhelmingly, respondents mentioned "freedom" as the thing they like the best about their new homes and what makes it comfortable for them. One woman noted, "I have more freedom...I have two guitars." Another participant mentioned that he did not like the way that staff at Mayview told him what to do and when to do it. "Now, I take a shower when I want to take a shower," he said.

Participants also discussed the qualities of a residence that make it feel most like home to them. Many residents stressed the need for privacy and a place to themselves. One participant declared, "I ain't got to be bothered with nobody else...I came a long way to get my own place." Another respondent believes that mental illness "decreases" when "people leave you alone." Perhaps this respondent said it best when he elaborated, "When you lose your privacy, that's one of the most stressful positions to be in. Without privacy, you just don't act the same. You exhibit instability, based on the loss of the privacy. Privacy gives you confidence and self-esteem. You can be yourself. When they take that away from you, you're constantly acting out." Other qualities of home that participants mentioned are surroundings and people that inspire comfort. One participant appreciates that the staff and residents of her home like her. "I can tell a joke, and nobody criticizes me." Another participant calls his residence his "comfort zone" and describes it as "a place where I can relax, listen to some music...do some reading." While the majority of participants have had positive experiences in their residences, they also look forward to being able to move out of them and live on their own. One respondent describes home as "sitting at home by the fireplace channel, eating some marshmallows...Eventually, I will get there." Another participant would like to be more "financially capable" so he can buy a house or have a bigger apartment. He says that he is ready for "another level of that comfort zone."

### *The promise and peril of choice*

Throughout the study we observed some participants who experienced excellent adjustment and outcomes. We met people who developed relationships, found work, and participated in volunteer activities. This subgroup of people was able to take advantage of opportunities developed in the system, and also to create their own opportunities.

Additionally, throughout the four-year study period a small number of participants exercised their freedom to continue or renew risky behaviors. These people particularly valued the freedom and choice

that community settings offered compared to the hospital. One noticeable pattern in this small group was to use illegal substances with old (and sometimes new) friends, and some of these people experienced significant consequences in the criminal justice system. Four men experienced significant periods of incarceration. One stole a parent's car, the others were charged with a parole violation, panhandling, public intoxication, alcohol and drug related disorderly conduct, and one had two assaults on others.

### *Quantitative results: Overview*

We used the best research validated instruments in six areas to quantitatively gauge outcomes for people discharged from Mayview when it closed. The areas were chosen because of their importance in assessing quality of life and well-being for people with severe mental disorders. The six areas are 1) Psychiatric symptoms, 2) Attitudes towards medication, 3) Social functioning, 4) Quality of Life, 5) Progress towards recovery and 6) Satisfaction with services. Some of these areas were tracked with multiple indicators.

In addition, we quantified "restrictiveness" of housing, and also tracked that indicator over time.

As will be seen in the detailed description below, each area had indications of improvement over the four year study. All indicators that did not improve were stable over time. In addition, the scores reported for this group compare favorably to other published findings.

The following sections provide detailed description of measurement and results for indicators measured with standardized instruments.

### ***Psychiatric symptoms***

Psychiatric symptoms were assessed with the BPRS (Overall & Gorham, 1962). The BPRS is an interviewer-rated checklist of 18 symptoms of major mental illness, and is the most widely used research measure of psychiatric symptomatology (Burns, 2007; Mortimer, 2007). It is highly sensitive to change, and can be accurately rated by a variety of clinical and research staff (McGorry et al., 1988; Mortimer, 2007; Overall & Rhoades, 1982).

Interviewers were trained to reach a criterion of agreement with accepted standards, receiving 10-20 hours of training and practice to reach the criterion. Agreement was checked periodically throughout the study period. The BPRS was rated at every standardized assessment, and at some check in visits.

Ratings for BPRS items range from 1 (not present) to 7 (extremely severe). BPRS totals range from 18 (if each of the 18 symptoms is rated 'not present') to 126 (if each of the 18 symptoms is rated 'extremely severe'). Leucht and colleagues (2005) developed cut-points for the BPRS to correspond with mild, moderate, and severe levels of illness by linking BPRS scores with Clinical Global Impressions for 1,979 participants with schizophrenia in seven drug trials. They report that "mildly ill" equates to a BPRS score of 31, "moderately ill" to 41, and "severely ill" to 53.

The analysis is based on 500 observations of the 92 participants in the study. Changes in psychiatric symptomatology were modeled with latent growth analyses using SAS Proc Mixed.

Psychiatric symptomatology decreased for the first two years, and then increased. We tested this pattern by centering the data on 24 months, and testing a curvilinear model using a quadratic growth term. The model included terms for the intercept, time, and time-squared. The quadratic term (time-squared) was highly significant,  $t(399) = 5.65$ ,  $p < .0001$ .

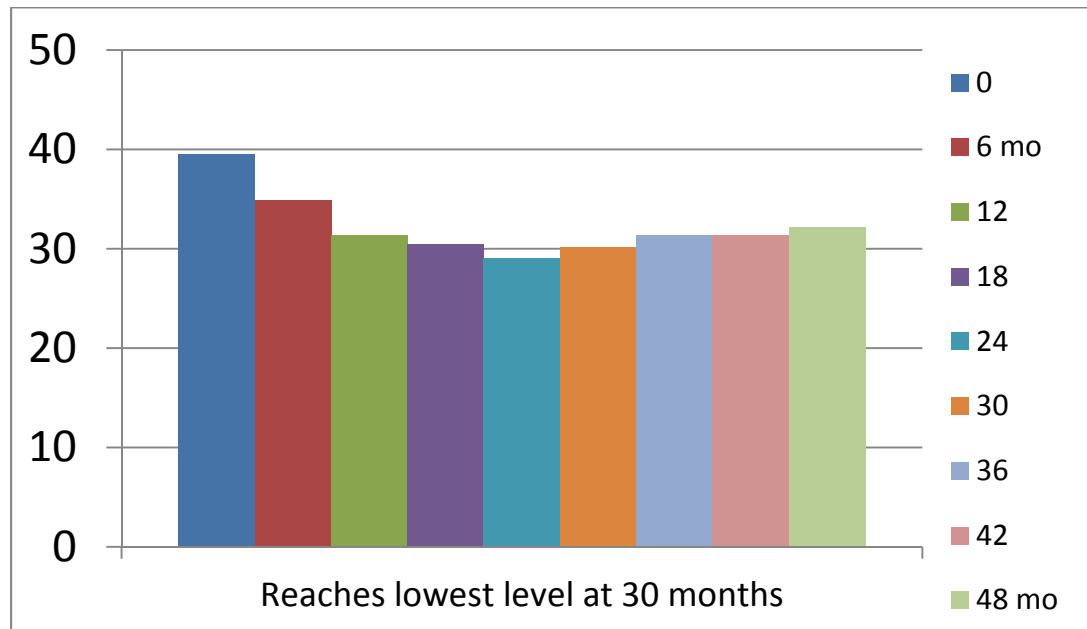
Analyses were repeated to account for the relatively small number of people recruited while still in the hospital, where symptoms were the highest. The pattern of results was confirmed when analyses were limited to the 19 people recruited in the hospital, and also when analyses were limited only to timepoints following hospital discharge (from 6-48 months).

Results are summarized in the Table and Figure below.

Table 5: BPRS means over time

	Hosp	6 mo	12 mo	18 mo	24 mo	30 mo	36 mo	42 mo	48 mo
	19	40	50	50	59	54	60	66	58
BPRS	39.5 (14.6)	34.9 (13.8)	31.3 (10.9)	30.4 (10.7)	29.0 (9.1)	30.2 (9.4)	31.4 (12.8)	31.3 (8.7)	32.2 (11.2)
% with BPRS $\geq$ 41	42%	20%	16%	16%	13.6%	9.3%	13.3%	13.6%	15.5%

Figure 1: Percent with at least moderate illness (BPRS  $\geq$  41)



### *Symptom remission*

Andreasen and colleagues (2007) proposed criteria for remission of symptoms of psychotic illness. They define remission as a state in which symptoms are reduced to low levels unlikely to affect behavior or well-being, and are maintained at these low levels for a substantial period of time. Symptom remission is a more limited construct than recovery, which focuses on establishing meaning and satisfaction, and successful functioning in community, social and vocational roles. Nonetheless, it is clear that at least for some people, the reliable reduction of symptoms to less bothersome levels is likely to improve quality of life, and may serve as a precursor to other important areas of recovery, such as social or vocational functioning.

Andreasen and colleagues propose that symptoms of schizophrenia can be considered to be in remission when BPRS scores on seven items related to psychosis have been observed to be no more than mild for at least six months. The symptoms included in the rating of remission are grandiosity, suspiciousness, unusual thought content, hallucinations, conceptual disorganization, posturing, and blunted affect. We have also examined this criterion for remission in the context of an overall BPRS of less than 31, the cut-point associated with mild illness in the Leucht et al. analysis.

We considered participants to be in remission if they had two consecutive observations within one year of each other that met the criteria for mild symptoms described above. We calculated the rate of remission for Year 2 and for Year 4 of the study.

Remission could be assessed for 62 of the 65 people who participated in the first two year phase of the study. 31 of 62 people (50%) met criteria for remission of psychotic symptoms, and 23 of these people (74%) at low symptoms overall.

Remission could be assessed for 75 of the 78 people who participated in the second two year phase of the study. 28 of 75 people (37%) met criteria for remission of psychotic symptoms, and 22 of these people (79%) also had low symptoms overall.

### ***Attitudes towards medication***

Medication is a part of daily life for most people discharged from the hospital. Medication regimes are demanding, and side effects can be significant. How people perceive the usefulness and side effects of their medication is thought to be related to whether or not people will take them.

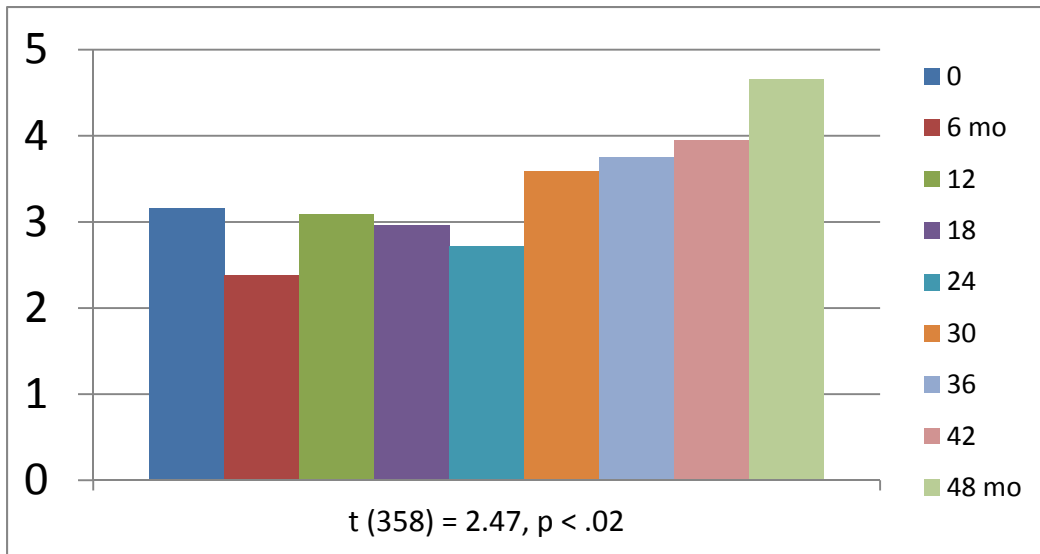
The Drug Attitude Inventory 10-item version (DAI-10) measures subjective response to medication. The items measure negative experiences (“I feel weird – like a zombie – on medication”) and positive experiences (“My thoughts are clearer on medication”). Participants rate each item as true or false, and items are then coded as +1 (for positive perceptions of medication) or -1 (for negative experiences with medication). Scores on the inventory range from -10, completely negative, to +10, completely positive. Scores of less than 0 have been considered as indicative of negative perceptions with medications that could lead to medication discontinuation.

Attitudes towards psychotropic drugs became more positive over the course of the study. Average scores are in the low positive range, and varied between a low of 2.38 at the six month observation to a high of 4.66 at the 48 month observation. Between 22 and 34% of people at each time point report scores less than 0, representing negative perceptions of medications. This percentage did not increase outside of the hospital, or change over the study time period.

*Drug Attitude Inventory*

	Hosp	6 mo	12 mo	18 mo	24 mo	30 mo	36 mo	42 mo	48 mo	F for time
N	19	39	46	50	53	52	56	63	53	
DAI-10	3.16 (6.26)	2.38 (5.48)	3.09 (5.73)	2.96 (5.35)	2.72 (5.86)	3.59 (5.28)	3.75 (5.30)	3.95 (4.63)	4.66 (4.82)	t (358) = 2.47, p < .02
% negative about medication	26%	28%	33%	24%	34%	25%	27%	22%	22%	F (7, 392) = .68, NS

Figure: Attitudes towards medications improve.



Average scores and percent of people reporting scores of less than 0 are similar or better than results reported in studies of other community-dwelling samples of people with serious mental disorders (Dassa et al., 2010; De las Cuevas & Sanz, 2007). Dassa and colleagues provide the estimate of negative attitudes towards medication that is most comparable to the work reported here. They conducted a one-week survey in the fifteen hospitals serving the south eastern region of France, and asked all people with a diagnosis of schizophrenia not in immediate need of hospitalization to complete the DAI. They report that 30% of these people were more negative than positive about medications according to this instrument. De las Cuevas and Sanz surveyed more broadly across diagnostic groups. Their survey included all people attending community mental health outpatient services on La Gomera Island in the

Canary Islands. 26% of these outpatients were diagnosed with schizophrenia; the remainder of the sample included mood, anxiety, somatoform and “stress-related” disorders. The mean for DAI score was 3.6 (SD = 4.1) in this outpatient sample, and 23% reported scores of 0 or less on this instrument.

### Residential restrictiveness

Developing housing options and finding housing that would meet the needs of people affected by the hospital closing was a particular focus of the closing process. Discharge plans focused on finding the least restrictive living situation in which people would be safe and well-served.

People were discharged into many different types of living situations, some of which were nearly as restrictive as the hospital. The goal of many individuals, and in many cases, the goal of the service system, is to

For people discharged to more restrictive settings, subsequent relocation to less restrictive settings can be an important personal goal. It can also be an important goal of the service system, which provides guidelines for time limits for some types of living situations, although the guidelines are not always enforced. Participants value freedom and choice highly, and finding safe and comfortable housing with as few restrictions as possible is an important personal and system goal.

*Quantifying restrictiveness.* We rank-ordered types of housing from least, to most, restrictive, and assessed whether restrictiveness decreased over time. Our rankings were 1) private home, boarding house, or cooperative apartment, 2) supported housing, 3) group home, 4) CRR, 5) PCH, 6) LTSR, 7) nursing home, 8) inpatient and 9) incarcerated.

Participants’ moved to less restrictive housing during the four-year study period. The average dropped from 5.22 at the 6-month observation to 4.25 at the 48-month observation,  $t(370) = -2.34, p < .02$ . The analysis included 463 observations of 92 participants. The following figures and tables represent this, and also show where people lived by type of housing to provide a more detailed context.

*Average of rank-ordered “restrictiveness” of housing, 6-48 months.*

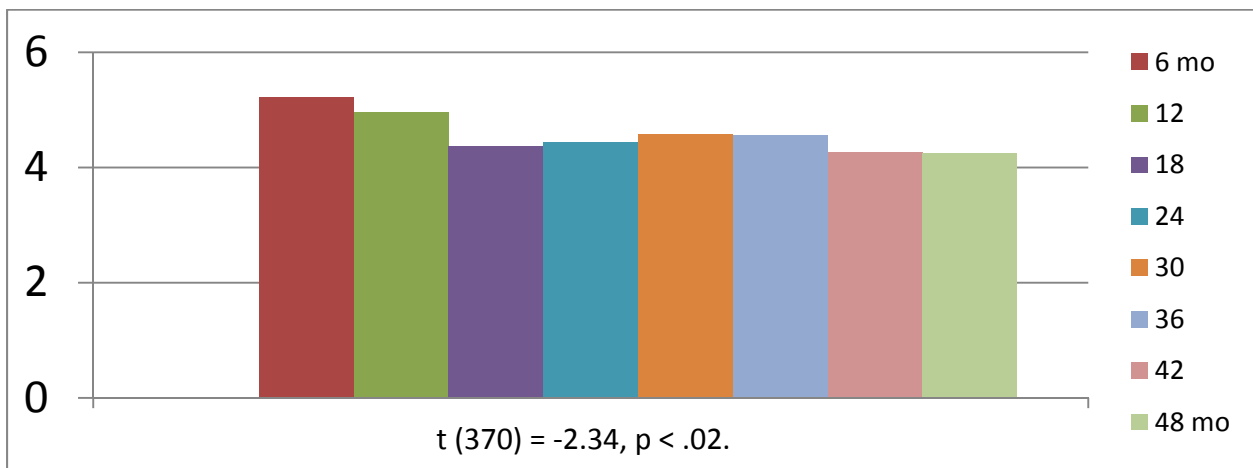
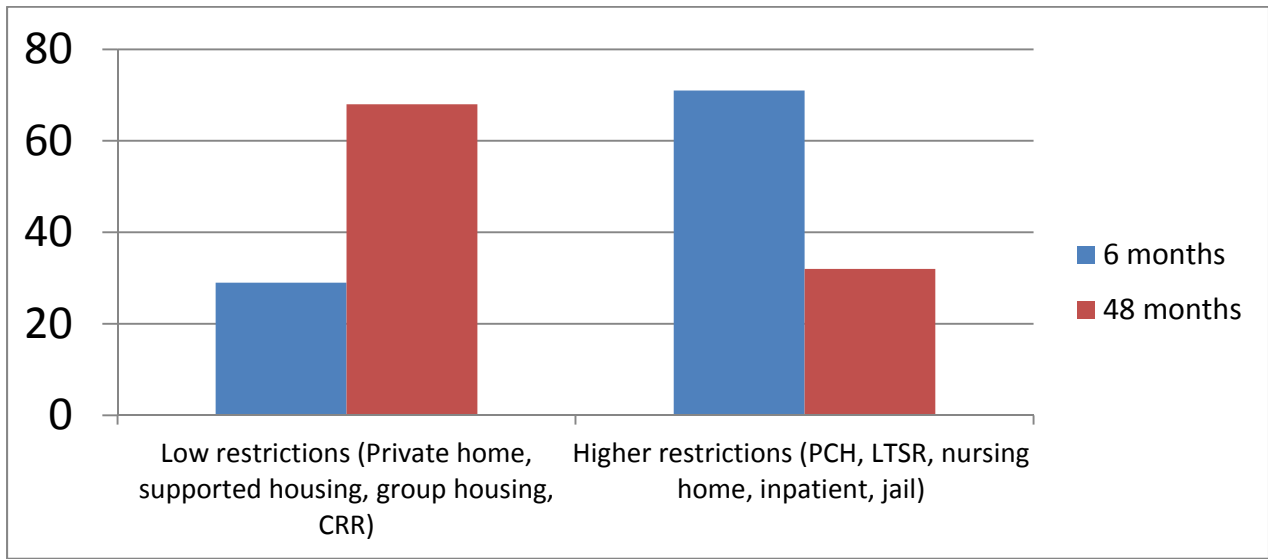




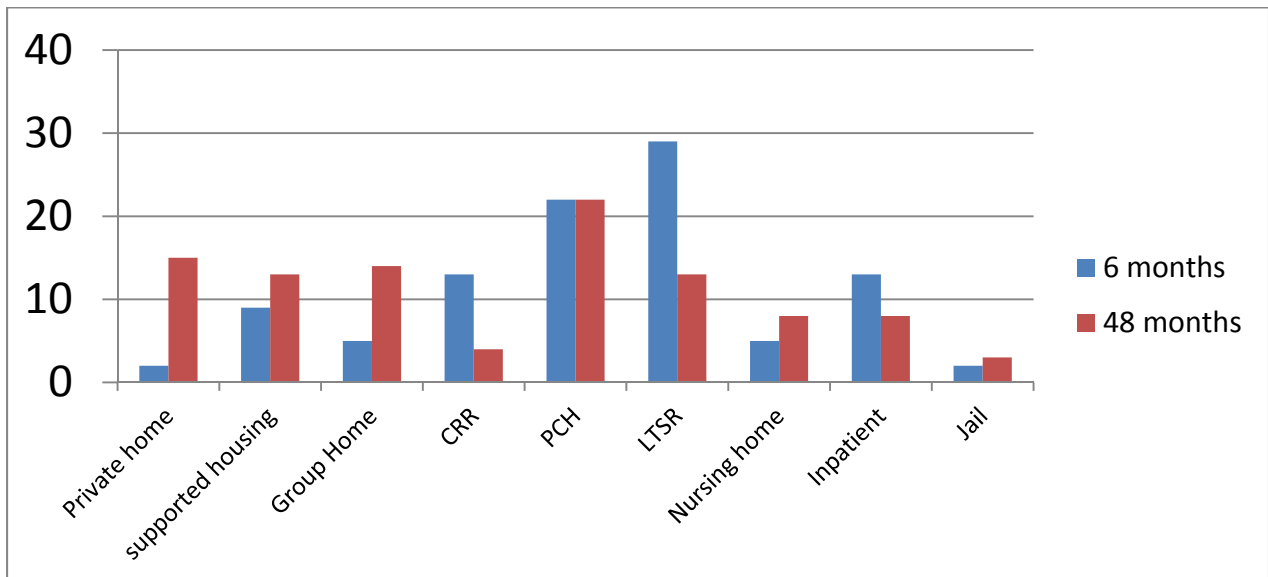
Table of means

	Hosp	6 mo	12 mo	18 mo	24 mo	30 mo	36 mo	42 mo	48 mo	Change
	19	40	50	51	58	56	61	67	60	N=85, obs=378
Restrict	8.00 (0)	5.22 (1.80)	4.96 (1.89)	4.37 (2.15)	4.43 (2.29)	4.57 (2.23)	4.56 (2.13)	4.27 (2.13)	4.25 (2.24)	t(292)= 3.52, p<.0005

Percent of people in less, and more, restrictive living situations, at 6 and 48 months



Percent of people in various housing situations at 6 and 58 months, details



Living situations at 6 and 48 months, detailed description

	Independent	Supported	Group home	CRR	PCH	LTSR	Nursing home	Hosp	Jail
6 months	1 (2%)	4 (9%)	2 (4%)	6 (13%)	10 (22%)	13 (29%)	2 (4%)	6 (13%)	1 (2%)
48 months	11 (15%)	9 (12.5%)	10 (14%)	3 (4%)	16 (22%)	9 (12.5%)	6 (8%)	6 (8%)	2 (3%)

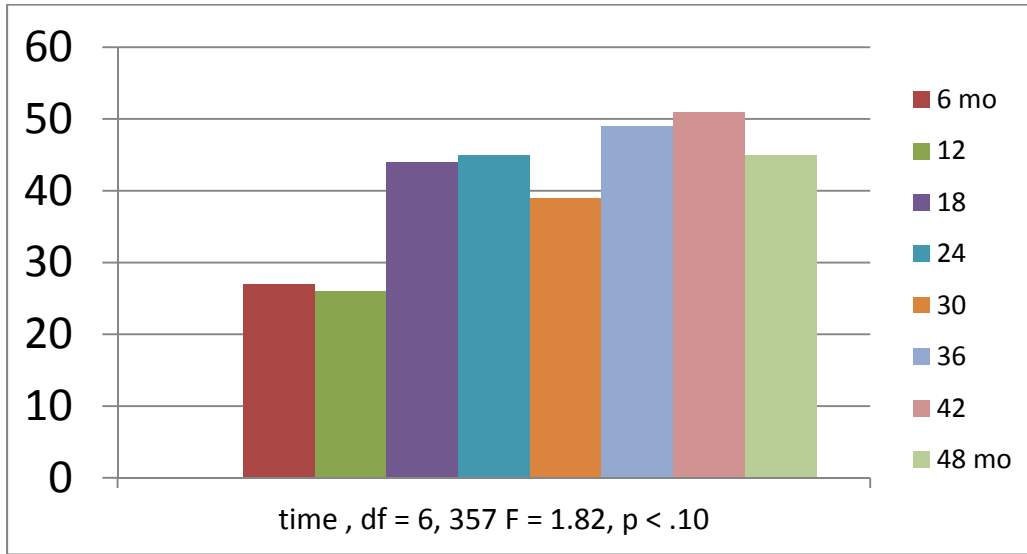
***Social life and social adjustment***

Developing and maintaining supportive social relationships is a key component of well-being in general, and particularly for recovery for the participants discharged from Mayview. Having lived in the closed community of the hospital, sometimes for considerable lengths of time, discharge brought them both challenges and opportunities in this domain. In the hospital, patients have little control over with whom they interact, and are geographically distant from family and friends; however, the hospital also provides a built-in community of people to interact with. One of the goals of leaving Mayview was to improve the social and relational landscape.

We used two instruments to measure social life and social adjustment. The Social Networks/Social Support interview (Estroff & Zimmer, 1994, Estroff et al., 1995) asks people to report how many people they see in various social roles, and we use it to report objective indicators of whether people received visits from family and friends. We also used the Social/Leisure subscale from the Social Adjustment Scale (Schooler, Hogarty & Weissman, 1979). Nine probes are used to elicit information about whether people are engaged in social life and leisure activities, and whether they are experiencing difficulties in these areas. Interviewer ratings of the nine areas result in an overall numeric score for social adjustment that is frequently used in psychiatric research.

*Regular contact with friends.* The number of participants who reported seeing friends regularly increased over the course of the study, although the trend for time did not reach statistical significance. By the four year anniversary of the closing about 45% of participants reported regularly seeing friends.

See friends regularly (percent)



*Regular contact with relatives.* About forty percent of participants report seeing family members at least once a month, and this percentage was fairly consistent throughout the study period. The visiting family members were diverse, and siblings were the most common visitors. For example, at the 24 month time period, 20 of 59 participants reported seeing family regularly, and these family members included a spouse (N=1), mothers (N=5), fathers (N=3), adult children (N=3), siblings (N=6), and uncles, aunts or other extended family members (N=2). Frequently these visitors were accompanied by other family members and/or friends.

When family and friends are considered together, a majority of participants report that they have regular social contact. Between 50 and 70% of participants at each time point reported that they had been seeing either friends, or relatives (or both) at least once a month.

	Hosp	6 mo	12 mo	18 mo	24 mo	30 mo	36 mo	42 mo	48 mo	F for time
N	17	37	49	48	55	54	59	65	56	
See friends at least monthly	6 (35%)	10 (27%)	13 (27%)	21 (44%)	25 (45%)	21 (39%)	29 (49%)	33 (51%)	25 (45%)	F(6, 357) = 1.8, p < .10
See family at least monthly	6 (35%)	15 (41%)	17 (35%)	18 (38%)	20 (36%)	21 (39%)	20 (34%)	26 (40%)	24 (44%)	F(7, 369) = .17, NS
See friends or family at least monthly	11 (65%)	21 (57%)	25 (51%)	29 (60%)	36 (65%)	31 (57%)	39 (66%)	47 (71%)	36 (64%)	F(7, 373) = .85, NS

Many people who were not seeing friends or relatives regularly reported that they would like to. Across the nine study time points, between 56% and 90% of the people who reported not having regular social contact said that they would like visitors.

*Would like visitors (if not seeing family or friends regularly)*

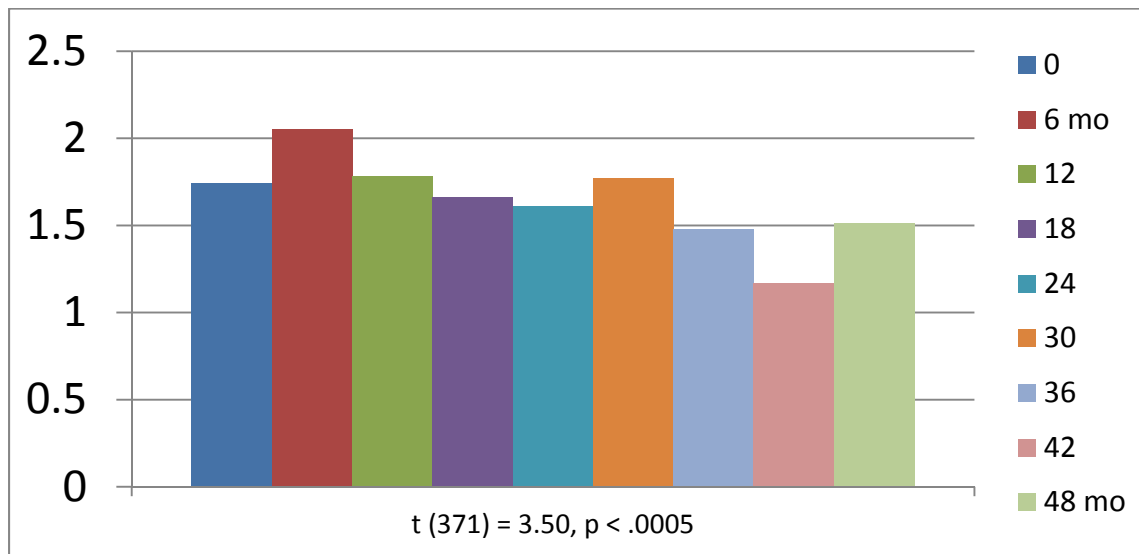
N	4	16	21	19	18	20	17	18	16
Would like visitors	3 (75%)	11 (69%)	19 (90%)	16 (84%)	15 (83%)	15 (75%)	11 (65%)	12 (67%)	9 (56%)

*Social life and leisure: standardized interview rating*

An addition indicator of social adjustment derived from the Social/Leisure subscale of the Social Adjustment Scale-II (SAS-II; Schooler, Hogarty & Weissman, 1979). The SAS-II is a well-validated, widely used measure of social adjustment in people with severe mental disorders (Priebe, 2007). It consists of nine probes that address contact with friends, opportunities for leisure activities, and social comfort and friction. Interviewers ask the probes conversationally (for example “What kinds of things do you do in your free time”, with follow-up probes as necessary), and then rate each item from 0 (no social impairment) to 4 (substantial social impairment). All answered probes are averaged, and overall score ranges from 0 to 4, with lower scores indicating better social adjustment. There are no published cut-points, however, the anchors associated with each problem provide guidance about interpretation of the scores.

Our results showed both that social functioning in this group of people is good, and also that it improved over the four years. Average scores at the nine study time points ranged from a high of 2.02, observed at six months post discharge and indicating the highest level of social dysfunction to a low of 1.17, observed at the 42 month follow up and indicating the lowest level of social dysfunction. An examination of item responses in this range indicate that the level of social activity and adjustment is quite high. Item anchors in this range suggest that participants see friends and families twice a month or more, usually talk easily with someone they consider a friend, experience only mild friction with others, and recover quickly if they feel hurt or offended in social interactions.

### *Social functioning on the SAS-II improves over time*



These means compare favorably with other published similar samples. 91 people with schizophrenia were recruited during an inpatient admission to a university hospital in Germany and followed for one year reported an average SAS score of 3.6 (SD = 1.2) (Wittorf et al, 2008). 81 men with schizophrenia who completed a treatment trial including social skills training or a support group reported means of 2.5 – 3.2 at the completion of treatment (Marder et al., 1996). Both of these research samples show substantially poorer functioning than the Mayview group followed here.

### **Quality of Life**

Quality of life has been a very active area of research in the study of the long-term adjustment of people with psychiatric disabilities. The ability to enjoy life and find meaningful activities, and whether the environment supports meaningful and enjoyable activities is core to recovery goals, and to human life.

We administered the World Health Organization Quality of Life Scale, Brief Version, (WHOQOL -Bref). This is a well standardized scale that has been used with many populations, including people with severe and persistent mental disorders. It was developed to accurately capture aspects of life that are known to be associated with overall well being and quality of life in order to assist epidemiologists and public health planners track this key indicator of societal health across nations over time. It was designed so that it could be used with both sick and well populations. The domains, and many of the items, are compatible with and indicative of components of recovery. For example, the items inquire about whether life is meaningful, satisfaction with capacity for work, and satisfaction with personal relationships. The environment subscale directly addresses a number of areas of interest, including perception of safety, the healthfulness of the physical environment, and whether finances support daily needs.

The instrument is composed of 25 items, each rated from 1 to 5, with lower scores representing lower quality of life. All subscales are rescaled and presented on scales from 0-100, for ease of comparison. Higher scores are associated with higher quality of life. The table shows change over time.

*Quality of life stable or improving over time*

	Hosp	6 mo	12 mo	18 mo	24 mo	30 mo	36 mo	42 mo	48 mo		
	17	38	47	49	48	51	55	63	54		
<i>How would you rate the quality of your life? (1 item)</i>											
	67.6 (30.3)	65.8 (33.1)	72.9 (27.5)	74.5 (24.7)	69.3 (25.4)	74.0 (26.9)	73.2 (28.8)	75.0 (24.6)	75.0 (21.7)	t(347) = 1.38, NS	
<i>How satisfied are you with your health? (1-item)</i>											
	61.8 (38.6)	64.5 (32.2)	69.7 (31.7)	69.9 (28.4)	65.3 (33.0)	64.7 (30.9)	67.3 (30.4)	66.3 (30.2)	63.2 (31.2)	t(347) = 1.27, NS	
<i>"Physical health": e.g. How satisfied are you with your ability to perform daily activities?</i>											
	63.6 (17.4)	60.7 (18.9)	68.3 (15.8)	66.1 (16.4)	65.1 (19.2)	67.8 (15.1)	67.2 (18.8)	70.1 (17.5)	70.3 (15.1)	t(346) = 2.01 p < .05	
<i>"Psychological well-being": e.g., How satisfied are you with yourself?</i>											
	59.8 (19.0)	58.4 (16.5)	62.1 (17.5)	63.3 (14.2)	62.6 (16.7)	64.6 (14.9)	61.3 (17.5)	63.9 (16.3)	63.5 (21.7)	t(345)= 1.03 NS	
<i>Social relations: e.g. How satisfied are you with your personal relationships?</i>											
	58.8 (31.5)	66.7 (21.5)	71.8 (22.2)	69.3 (24.4)	69.0 (24.0)	68.0 (27.7)	66.7 (25.4)	71.5 (24.8)	72.8 (23.7)	t(338) = 1.3, NS	
<i>Environment: e.g., How safe do you feel, have you enough money to meet your needs</i>											
	61.4 (21.0)	59.2 (20.1)	64.6 (18.6)	65.9 (18.6)	63.3 (20.5)	64.4 (22.1)	69.1 (20.2)	70.1 (18.0)	71.4 (19.7)	t(345) = 3.01, p < .003	

The WHOQOL Brief has been quite widely used to chart quality of life for people with mental illness since it has become available. Participants in this study compared favorably to other people with severe mental disorders for whom quality of life has been examined. This table summarizes a number of studies that have employed this instrument. We have arranged the studies in the order of the average score on the WHOQOL score for Psychological Well-Being. Each study reported averages using a common scoring technique, or provided sufficient information that scores could be transformed onto the standard scale for this level of comparison.

	Psychological well-being	Physical Health	Social Relations	Environment
People hospitalized with schizophrenia in Taiwan Kao et al., 2011	48.5	53.8	49.6	47.8
People with schizophrenia recruited from university-based outpatient services in Taiwan. Yen et al., 2008	49.1	55.3	50.4	46.0
Community-dwelling people with schizophrenia treated in Barcelona Mas-Esposito et al., 2011	51.1	57.8	40.9	57.8
Healthy control volunteers recruited through advertisements in Taiwan Yen et al., 2008	54.5	70.8	62.2	51.9
US WHOQOL instrument validation sample (includes sick and well people) Skevington et al., 2004	61.2	71.9	57.5	48.1
<b>Mayview sample, 2-years post-discharge</b>	<b>63.9 (17.7)</b>	<b>66.5 (19.3)</b>	<b>68.6 (22.9)</b>	<b>63.4 (20.6)</b>
People with schizophrenia receiving outpatient treatment in Austria Hofer et al., 2006	64.5 (17.4)	69.3 (14.2)	62.1 (21.7)	73.8 (11.9)
<b>Mayview sample, 4-years post-discharge</b>	<b>63.5 (21.7)</b>	<b>70.3 (15.1)</b>	<b>72.8 (23.7)</b>	<b>71.4 (19.4)</b>
Representative sample of residents of Denmark Noerholm et al., 2004	69 (16)	77 (17)	69 (18)	74 (16)
Representative sample of residents of Victoria, Australia Hawthorne, Herrman & Murphy, 2006	71 (14)	73.5 (18)	72 (18)	75 (13)

These are roughly rank ordered. For ratings of satisfaction with social relations and the environment, the Mayview sample compares well to community samples in Denmark and Australia, which are the two samples with the highest quality of life. The Mayview sample does not fare as well as these community samples in quality of life related to psychological or physical health, but compares very favorably to samples of people with schizophrenia. They are doing much better than samples of people with schizophrenia from Taiwan and Barcelona, and they are comparable or better than a sample of people with schizophrenia in Austria.

### ***Progress towards recovery***

Recovery is perhaps the most important construct to emerge in mental health treatment in the last thirty years. It has its origins in research (Jobe & Harrow 2005), the lived experiences of community, grassroots advocates and people experiencing mental illness. While recovery can mean different things to different people, its core ideas are that autonomy, purpose, self-worth, choice, opportunity and meaningful activities are goals for all people, and that successful service systems will support development in these areas. Definitions and measurement are still actively evolving. (Leamy et al. 2011)

We measured progress towards recovery with the Recovery Assessment Scale (Corrigan et al., 1999, Giffort et al., 1995, McCabe, Saidi & Priebe, 2007). The 41 items of the original version of the RAS were developed from the illness and recovery narratives of four consumers, which were abstracted by researchers, and then verified and expanded upon by 12 consumers (Giffort et al., 1995). Subsequent exploratory and confirmatory factor analyses showed that 24 items reliably constituted five factors (Corrigan et al., 2004; McNaught et al., 2007); the list was later revised to 22 items. Each item is rated from 1 (strongly disagree) to 5 (strongly agree), and higher scores are associated with more positive attitudes towards recovery. The five subscales include: *Personal Confidence and Hope*; *Willingness to Ask for Help*; *Goals and Success Orientation*; *Reliance on Others*; and, *Not Dominated by Symptoms*.

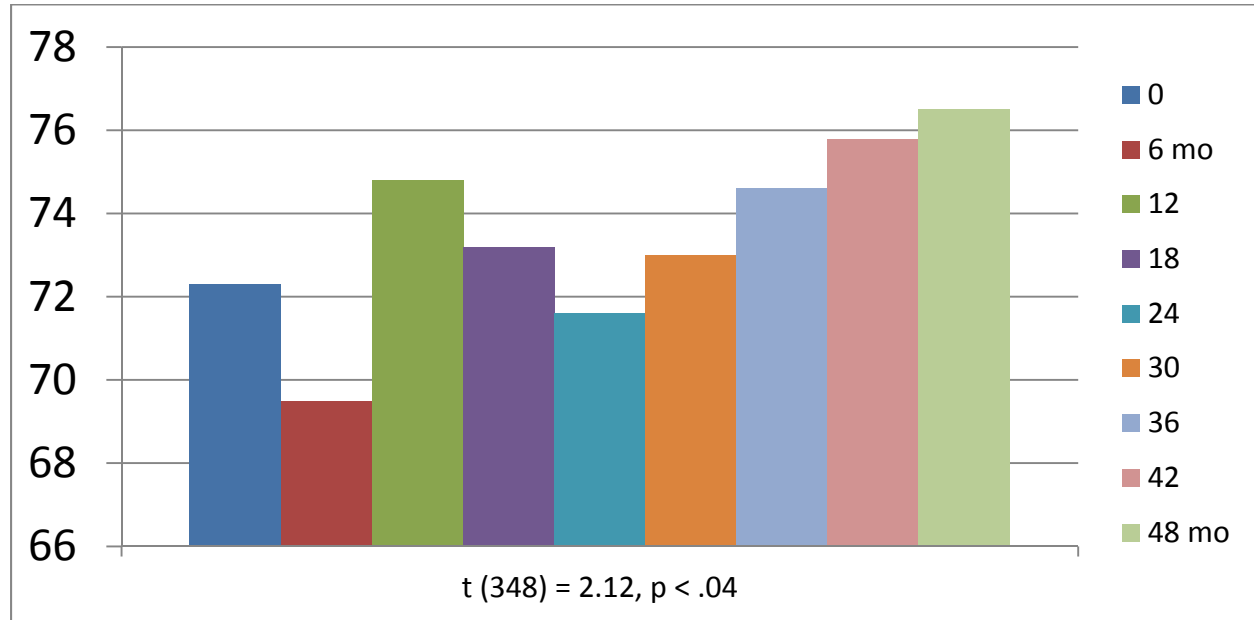
Scores are calculated by adding items. Some authors re-scale each item to range from 0-4 (from the original 1-5). When this is done, the lowest possible score for all subscales is 0. Whether or not this is done, subscales with more items have a wider range of possible values than subscales with fewer items. The Not Dominated by Symptoms subscale includes 3 items, and thus ranges from 0 to 12, with 12 representing the highest possible value, or the equivalent of the best recovery outcome in that area. The Goals and Success Orientation subscale includes 5 items, and thus ranges from 0 – 20. A score of 20 on the Goals and Success Orientation subscale is roughly equivalent to a score of 12 on the Willingness to Accept Help subscale.

These findings underscore the extended time frame and episodic, incremental processes of recovering that is well documented by researchers (Schrack & Slade 2007). As Topor and colleagues (2009) explain, recovery occurs both within and around the individual, and involves shifts in relationships with friends, family, and mental health professionals. None of these changes happen rapidly. Providing the foundations and environment for consumers' varied pathways, along with those of the mental health system, is a reasonable first phase after discharge.

The overall score, and two of the five subscales (Personal confidence and hope, and reliance on others), improved over the four years of the study, and the other three indicators remained stable.



Total score for the Recovery Assessment Scale (24-item version) improves over four years



RAS: Table of results

	0	6	12	18	24	30	36	42	48	
	19	39	48	49	51	52	52	59	54	N=92, obs = 439
RAS24	72.3 (16.0)	69.5 (17.0)	74.8 (14.8)	73.2 (14.0)	71.6 (14.0)	73.0 (16.3)	74.6 (13.5)	75.8 (12.0)	76.5 (14.3)	t (348) = 2.12 p < .04
<sup>1</sup> Personal Confidence and Hope	26.5 (6.5)	25.6 (7.8)	28.6 (6.0)	27.8 (6.9)	27.1 (6.3)	27.6 (6.4)	27.9 (5.6)	28.2 (5.6)	28.8 (5.8)	t (346) = 2.03, p < .04
<sup>2</sup> Willingness to ask for help	9.24 (2.5)	9.22 (2.2)	9.87 (1.84)	9.48 (2.34)	9.37 (2.26)	9.26 (2.43)	9.88 (1.98)	9.63 (2.08)	10.08 (2.03)	t (346) = 1.01, p < .32
<sup>3</sup> Goal and Success Orientation	15.6 (4.0)	15.3 (3.9)	16.3 (3.6)	15.8 (3.7)	16.2 (3.3)	16.3 (3.7)	16.6 (3.2)	16.5 (3.1)	16.4 (3.0)	t (347) = 1.28, p < .20
<sup>4</sup> Reliance on others	12.2 (2.6)	12.0 (3.0)	11.8 (3.4)	12.5 (2.7)	12.0 (3.2)	12.1 (3.8)	13.0 (2.7)	13.0 (2.5)	12.9 (3.2)	t(347) = 2.8 p < .006
<sup>5</sup> Not dom by symptms	8.0 (2.7)	7.7 (2.9)	8.2 (2.6)	7.5 (2.8)	7.3 (2.9)	8.1 (3.4)	7.2 (3.0)	8.6 (2.3)	8.2 (3.1)	t (340) = 1.25, NS

<sup>1</sup>"I have an idea of who I want to become", "I'm hopeful about my future", and "I can handle stress"

<sup>2</sup>"I know when to ask for help", "I am willing to ask for help" and "I ask for help when I need it"

<sup>3</sup>"I have a desire to succeed", "I have my own plan for how to stay or become well", "I have goals in life that I want to reach"

<sup>4</sup>"Even when I don't care about myself, other people do", and "I have people I can count on"

<sup>5</sup>"Coping with my illness is no longer the main focus of my life", "My symptoms interfere with my life less and less" and "My symptoms seem to be a problem for shorter periods of time each time they occur"

The average scores for participants in this study appear to be better than other published reports of RAS scores. Andresen, Caputi, and Oades (2010) report on baseline data from the Australian Integrated Mental Health Initiative, a large, multi-site initiative investigating the Collaborative Recovery Model (Oades et al, 2005). 281 people with a diagnosis of a psychotic disorder and high needs as rated by a standardized assessment (the CANSAS, Phelan et al., 1995), were recruited by their case managers, and completed the RAS along with some other questionnaires. Their average score for the 41-item version of the RAS and the 5 subscales detailed by Corrigan et al. 2004 are shown in comparison to the Mayview participants at the two-year and four-year post-discharge time points. Corrigan and Phelan (2004) report on the baseline scores of 176 people with serious mental illness in Illinois at the time they were recruited to participate in a study of the effects of consumer operated services on a variety of consumer outcomes. (Their scores are rescaled to include 0 for comparison to the other samples.)

*RAS scores compare favorably to other populations*

	RAS total (41 item version) (0-164)	Personal confidence and hope (9-item version) 0-36	Willingness to ask for help (0-12)	Goal orientation (0-20)	Reliance on others (0-16)	Not dominated by symptoms (0-12)
<b>Mayview sample, 4-years post-discharge</b>	<b>130.5 (23.5)</b>	<b>28.8 (5.8)</b>	<b>10.1 (2.0)</b>	<b>16.4 (3.0)</b>	<b>12.9 (3.2)</b>	<b>8.2 (3.1)</b>
<b>Mayview sample, 2-years post-discharge</b>	<b>122.2 (24.7)</b>	<b>27.5 (5.6)</b>	<b>9.3 (2.3)</b>	<b>16.0 (3.3)</b>	<b>12.0 (3.2)</b>	<b>7.3 (2.9)</b>
People with serious mental illness participating in the Illinois site of the Consumer Operated Service Project Corrigan & Phelan, 2004		24.2 (6.1)	8.8 (2.4)	14.6 (2.7)	11.8 (2.7)	6.9 (2.8)
Australian sample of people with psychotic disorders Andresen, Caputi and Oades, 2010	112.4 (22.1)	23.4 (6.05)	8.5 (2.4)	14.2 (3.6)	11.9 (2.6)	6.8 (2.9)

Other studies with published RAS data tend to focus on associations across study variables, without reporting means, or do not report aspects of the scoring needed to understand how reported means compare to this study.

***Perceptions of Care***

Satisfaction with care is a key indicator of the quality of services. People discharged from Mayview moved into numerous types of supported residential and treatment facilities, and it is valuable to assess how they perceive their new settings.

We measured satisfaction with care using the Perceptions of Care survey (Eisen et al, 2002). This instrument was developed in response to recent interest in developing standardized instrumentation that can be used for benchmarking, quality assurance efforts, and accreditation across mental health

and substance abuse service settings. This instrument was designed to measure satisfaction with mental health and substance abuse inpatient and residential services. It consists of 21 items, 18 of which are usually reported as one-item tests of satisfaction with various aspects of services. A subset of items can also be combined to form subscales. Because some of the items appear in more than one subscale, they are reproduced below in their entirety. Individual items have varying response options; all items are rescaled so that they are equally weighted to be combined, and all subscales are scaled from 0 to 100.

At the two-year anniversary of the closing, it was noted that scores on the POC were flat throughout the first two years post-discharge, and that their levels did not compare favorably to the major published benchmark. This situation has notably changed. At the four year mark, each subscale of the POC shows improvement over time. Improvement in Interpersonal Aspects of Care showed particular improvement and is illustrated in the Figure. Furthermore, responses are now much more comparable to those in the major published benchmark study (which are reported item-by-item).

*Satisfaction with care increases over four years (POC)*

	Hosp	6 mo	12 mo	18 mo	24 mo	30 mo	36 mo	42 mo	48 mo	
	19	39	48	48	53	53	56	63	54	N = 92, Obs = 453
Information received	68.4 (35.9)	78.6 (31.0)	74.3 (30.7)	78.1 (28.2)	74.2 (34.4)	79.6 (29.9)	78.9 (29.0)	79.1 (27.9)	85.5 (26.7)	t(360)=2.08, p < .04
Interpersonal aspects of care	56.4 (26.4)	63.1 (25.2)	61.5 (28.0)	65.3 (25.2)	64.4 (25.2)	69.6 (25.2)	72.7 (22.9)	74.3 (23.0)	79.0 (22.1)	t (357) = 5.56, p < .0001
Continuity of care	60.5 (36.5)	67.4 (30.4)	68.8 (31.7)	70.1 (33.3)	70.3 (29.7)	76.9 (30.7)	73.7 (31.6)	73.3 (31.6)	81.1 (25.9)	t(359) = 3.35, p < .0009
Global evaluation of care	60.7 (27.7)	66.1 (26.0)	69.2 (27.1)	68.8 (27.9)	65.6 (28.4)	68.7 (28.3)	72.3 (27.0)	71.9 (26.5)	79.7 (23.1)	t(356) = 3.17, p < .002
POC tot	62.7 (25.6)	66.9 (21.9)	66.7 (24.3)	69.6 (22.2)	69.3 (22.7)	72.8 (22.0)	72.9 (21.3)	73.6 (20.7)	79.3 (20.0)	t (361) = 4.59, p < .0001

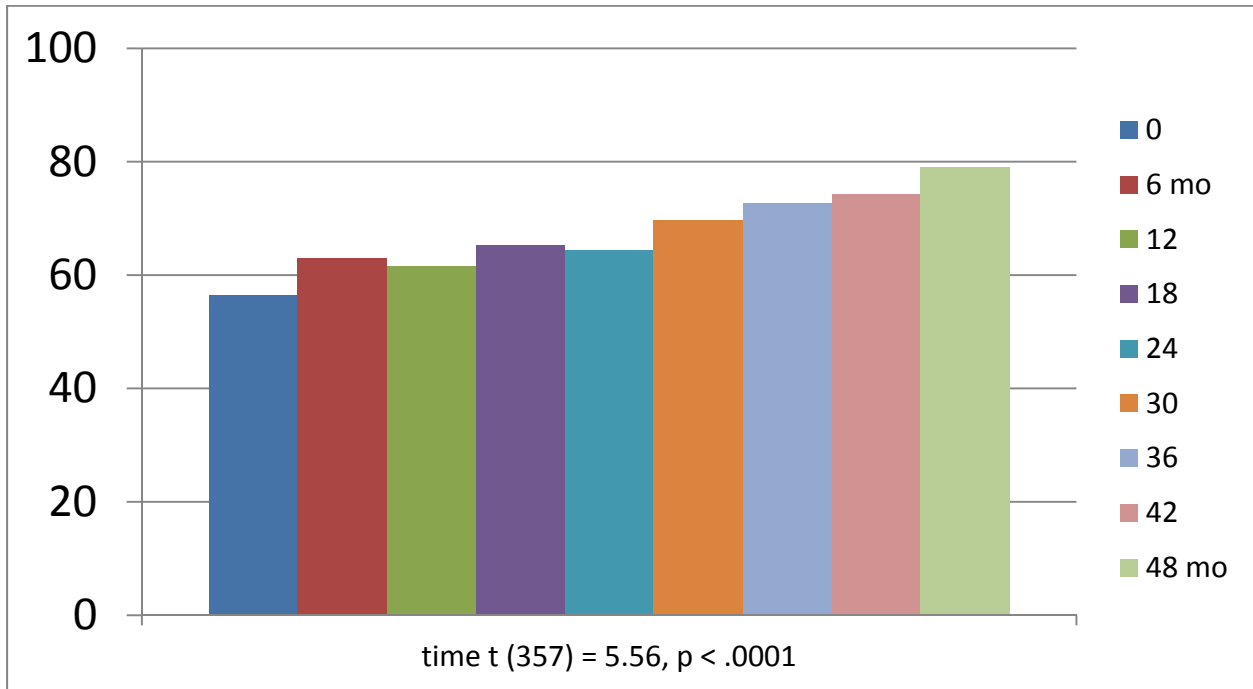
1 *Information received*: Did the staff tell you about the benefits and risks of medications you are taking? Did the staff give you information about your rights as a patient? Did the staff give you information about rules and policies of the program?

2 *Interpersonal aspects of care*: Did the staff give you reassurance and support? Were you involved as much as you wanted in decisions about your treatment? Did the staff listen carefully to you? Did the staff who treated you work well together as a team? Did the staff spend enough time with you? Did the staff treat you with respect and dignity? Did the staff explain things to you in a way you could understand?

3 *Continuity/coordination of care*: Did the staff tell you about the benefits and risks of medications you are taking? Did the staff review plans for your continued treatment? Were you told who to contact if you have a problem or crisis? Did the staff tell you about self-help or support groups? Did the staff give you information about how to reduce the chances of relapse?

4 *Global evaluation of care*: Did the staff give you reassurance and support? How much were you helped by the care you received? Using any number from 1 to 10, what is your overall rating of the care you received? Would you recommend this facility to someone else who needed mental health care?

*Perceptions of Interpersonal aspects of care improve substantially over four years*



Eisen and colleagues (2002) provide results for the POC across 14 mental health and substance abuse inpatient facilities, and included 6,972 participants. Average ratings on POC subscales are shown in contrast to the ratings made by participants in this study at the two-year time points.

Ratings may be rather higher in the Eisen et al. data for at least two reasons. They were unable to track the number of people who declined to complete the survey, and it is frequently the case that people who are dissatisfied with services choose not to complete surveys. Additionally, the 14 inpatient units surveyed were shorter-stay programs, and satisfaction with such units may be fundamentally different from satisfaction with long-stay residential-type programs. Nonetheless, it is worthwhile to note that a number of the item responses in the Mayview discharge study meet the criterion for initiating quality assurance interventions recommended by Eisen. She suggests that quality improvement activities be initiated for any item that receives less than 80% positive endorsement. If this standard were used, a number of targets for quality improvement could be identified, including staff listening carefully to consumers, working well as a team, explaining things in understandable ways, and involving consumers in treatment.

Perception of Care Items: Mayview sample and Eisen et al. National Sample.

	Mayview sample, 4 years post-discharge				Eisen et al., 2002											
	Yes N	%	No N	%	Yes N	%	No N	%								
1. Did the staff give you information about the rules and policies of the program?	58	84%	11	16%			6359	92%	553	8%						
2. Did the staff give you information about your rights as a patient?	59	87%	9	13%			6238	90%	678	10%						
14. Did the staff tell you about self-help or support groups?	53	78%	15	22%			5203	78%	1465	22%						
15. Did the staff give you information about how to reduce the chances of a relapse?	51	74%	18	26%			5047	77%	1532	23%						
3. Did the staff tell you about the benefits and risks of the medications you are taking?	55	80%	14	20%			5450	84%	1062	16%	Not taking medication 151 2%					
12. Did the staff review with you plans for your continued treatment after you leave the program?	59	86%	10	14%			5563	84%	434	6%	Unsure 658 10%					
13. Were you told who to contact in case you have a problem or crisis after you leave the program?	59	86%	10	14%	Unsure 2		4434	67%	1280	19%	Unsure 889 14%					
18. Would you recommend this facility to someone else who needed mental health or substance abuse treatment?	56	81%	2	3%	Unsure 11 16%		5441	83%	392	6%	Unsure 736 11%					
	Never		Sometimes		Usually		Always		Never		Sometimes	Usually	Always			
4. Did staff explain things in a way you could understand?	2	3%	11	16%	16	23%	40	58%	384	6%	774	11%	2179	32%	3553	52%
5. Were you as involved as you wanted in decisions about your treatment?	4	6%	17	25%	16	23%	36	48%	433	6%	1108	17%	2138	31%	3594	52%
7. Did the staff listen carefully to you?	3	4%	11	16%	20	29%	35	51%	150	2%	937	14%	2228	32%	3594	52%
8. Did the staff work well as a team?	4	6%	7	10%	18	26%	40	58%	161	2%	711	10%	2086	31%	3889	57%
9. Did staff spend enough time with you?	7	10%	10	14%	16	23%	36	52%	236	3%	1042	15%	2371	34%	3260	47%
10. Did the staff treat you with respect and dignity?	0	0%	9	13%	16	23%	44	64%	126	3%	1042	15%	2371	34%	3260	47%
11. Did the staff give you reassurance and support?	3	4%	11	16%	15	22%	40	58%	157	2%	851	13%	1889	28%	3747	56%
6. How much does the staff involve your family in treatment	More than I wanted 6	9%	Less than I wanted 13	19%	About the right amount 22	33%	None, which is what I wanted 26	39%	More than I wanted 383	6%	Less than I wanted 604	9%	About the right amount 3690	54%	None, which is what I wanted 2101	31%
16. How much were you helped by the care you received?	Not at all 5	7%	Somewhat 17	25%	Quite a bit 17	25%	A great deal 30	43%	Not at all 248	4%	Somewhat 1150	17%	Quite a bit 2448	37%	A great deal 2835	42%

From 1-10, what is your overall rating of care you are receiving?	1	2	3	4	5	6	7	8	9	10										
Mayview sample	4	6%	0	0%	2	3%	2	3%	5	7%	5	7%	5	7%	10	15%	6	9%	29	43%
Eisen et al., 2002	88	1%	82	1%	134	2%	177	3%	374	6%	338	5%	817	2%	1533	23%	1223	18%	1941	29%

**Table summarizing quantitative findings**

	Worsens	Stable	Improves
<i>Psychiatric symptomatology (BPRS)</i>			X *
<i>Attitudes towards medication (DAI)</i>			X
<i>Residential restrictiveness</i>			X
<i>Social life and social functioning</i>			
Social and leisure sub-scale, SAS-II			X
See family regularly (Social Networks Instrument)		X	
See friends regularly (Social Networks Instrument)			X (marginally)
<i>Quality of Life</i>			
1-item rating of overall "quality of life"		X	
1-item rating of satisfaction with health		X	
Quality of life related to physical health			X
Quality of life related to psychological well-being		X	
Satisfaction with social relationships		X	
Perception of safety and adequacy of environment			X
<i>Progress towards Recovery (RAS)</i>			
Overall score			X
Personal confidence and hope			X
Willingness to ask for help		X	
Goal and success orientation		X	
Reliance on others (Have others one can count on)			X
Not dominated by symptoms		X	
<i>Satisfaction with services (POC)</i>			
Information received			X
Interpersonal aspects of care			X
Continuity of care			X
Global evaluation of care			X
POC total score			X

## SUMMARY AND CONCLUSIONS

This study followed people discharged from Mayview State Hospital at the time of its closure, in order to learn whether the service system could support the most ill and vulnerable citizens in community-based settings. The study used the most rigorous available qualitative and quantitative methods to learn about people's experiences and track their outcomes.

This study tracked major indicators using rigorous sampling and measurement techniques, over four years. A major purpose of the study was to track whether outcomes deteriorated for people over time. There was particular concern that outcomes could deteriorate 2-4 years after the hospital closure, as the spotlight focused on the hospital closure in the early days would necessarily be turned to other pressing matters.

All indicators were stable or improving. More than half of the quantitative indicators measured improved, and each of seven areas of focus showed one or more indicators that improved. Importantly, most gains were seen, not in the initial phase, but in the 2-4 year phase of the study.

Survey-type data, while very efficient, lack depth, and survey-only studies can be unsatisfying in that they provide little context for the findings. In this study, findings were validated and extended with extensive qualitative observations. Qualitative findings were also largely positive. People were mostly safe and comfortable in their homes, with access to services that were designed to meet their sometimes very complex needs.

There is every reason for enthusiasm about these findings. They must also be taken within the context of the methodological limitations of the study.

The most serious methodological limitation is the problem of "adverse selection". People must freely consent to research procedures, and not all people will choose to participate. Our overall acceptance rate into the study was high, at 76%. However, 24% of people did not participate, and it is possible, indeed likely, that they are different from the people who chose to participate. There are no research procedures that allow for consent that can completely overcome this issue.

Furthermore, there are important adverse events that affected people's study participation. Despite our efforts, and the efforts of the mental health system on our behalf, it was almost impossible for people who were incarcerated to contribute standardized data. Thus, observations at which they may have been highly symptomatic and very dissatisfied are necessarily lost, and sometimes participants were lost for repeated observations due to troubles with the criminal justice system.

Finally, nine people, representing almost ten percent of the sample, died during the four year study. The most important concern here is the human dimension of their individual situations. From a technical standpoint, however, this group, who may have been highly symptomatic and very dissatisfied, do not contribute data to the final time points; that is, their adverse outcomes are removed from the overall summary of the standardized measures at the later time points.

Many of the participants who died were quite young at the time of their deaths. Only two people exceeded the US life expectancy of 79 years; four people died in their fifties, and one person was aged only 41 at the time of his death. While most people died of natural causes, at least one person died as a result of a serious violent episode related to his mental condition.

This situation raises important philosophical issues for the service system, and for society. The hospital is a very secure environment, but does not prevent death, even early, or even violent, death. Given the overwhelming preference that participants expressed for life outside of the hospital, it is unclear that permanent residence in very restrictive settings, which would reduce incarcerations and perhaps even somewhat prolong life, are desirable.

Our approach as research technicians is to be conservative about inferences that can be drawn, and we highlight these methodological issues in part to provide context for the main conclusions of the study, which are overwhelmingly positive. Every major area of study had one or more indicators of improvement over the four year study period, and no indicator deteriorated over time. Additionally, we collected extensive qualitative data. We visited participants regularly in their homes, had frequent conversations with them and their providers, conducted longer interviews with all participants who were able and willing to engage in such interviews, and recorded field notes at every visit. This greatly enhances the validity of the findings. Survey data is very useful to summarize outcomes for large groups of people, and has great advantages of efficiency of understanding and communicating results. However, it can be greatly limited, because it cannot capture nuance and context, which in this study, were critical. Our qualitative observations also strongly indicate that the large majority of participants are safe and comfortable in their homes, and that the service system is attending to their needs. There is room for improvement. However, observations, given the limitations of the study, show a group of people with high needs, whose needs are being met by the service system.



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