

Mayview Discharge Study

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This document reports on the progress of study of outcomes over four years for people discharged from Mayview State Hospital when it closed in December of 2008. The study originally planned to follow people for two years. Last year it was extended for an additional two-year follow up period. The first two years will be referred to in the report as "Phase 1" and years three and four post-discharge, now underway, will be referred to as "Phase 2".

This year's progress focused on three activities.

- 1) We completed observations for the first two years post-discharge, (Phase 1), and reported on outcomes from this phase.
- 2) We re-established and augmented the sample of participants for years three and four of the study.
- 3) We continued observations for years three and four of the study (Phase 2) on schedule.

1) First two years of study (Phase 1) completed.

Data collection for the first phase of the study was completed during 2011. This included completing 18- and 24-month standardized assessments of all participants in the first sample, completing check-in visits, and completing the first in-depth interview, which addressed participants' experiences with the relocation process. Two-year outcomes are summarized briefly below and were reported at the June 2011 stakeholders meetings.

The first two years of the study followed 65 people discharged from Mayview State Hospital when it closed in December, 2008. They represented 75% of 87 reachable and eligible people from a random sample of the people in the hospital who participated in the community support planning process linked to the closing. We saw participants every three months for two years. Research-validated standardized assessments were completed every six months. The intervening visits focused on qualitative data collection in the form of conversations with participants and providers, and interviews structured around well-being, satisfaction, and current adjustment. More detailed interviews were also conducted concerning experience with the closing procedures and relocation. Descriptive field notes were taken at every visit.

Participants overwhelmingly reported that they preferred community living to the hospital, captured in the statement "it's the freedom factor". Most participants felt safe and comfortable in their new residences. However, community integration is still a challenge for most participants, and many would like a greater variety of interesting activities to engage in. Qualitative observations also suggest that housing and therapeutic living situations will present on-going concerns.

Psychiatric symptoms decreased over time, with 60% of participants meeting a recently-published criterion for remission of psychotic symptoms, and 50% meeting this criterion also in the context of low or mild symptoms of other major mental disturbance. Indicators of social adjustment also showed improvement over the two-year observation period. Other indicators, including quality of life, progress towards recovery and perceptions of care did not change over the two-year time period. Compared to other similar samples, levels of quality of life and recovery were medium or high. In contrast, standardized ratings of satisfaction with care were rather lower than those seen in other populations, and suggest possible areas of quality improvement.

While people were overwhelmingly doing well, some participants experienced negative outcomes. Two participants died during the study period, and some participants experienced incarceration. Some participants were lost to follow up after significant involvement with the legal system began.

2) Re-establishing and augmenting the sample of participants

Long term longitudinal studies like this one can experience substantial attrition, threatening the representativeness of their samples. We took several steps to ensure the best representation possible for Phase 2 of the study.

We asked people participating in Phase 1 to agree to Phase 2, we contacted Phase 1 refusers, and we attempted to find people who were unreachable for Phase 1. This group included 90 people, five of whom could not be contacted, for a final list of 85 people to contact.

63 people agreed, for an overall acceptance rate of 75%. These 63 people included 56 Phase 1 participants, 6 Phase 1 refusers, and one person who was not reachable (by study personnel) at Phase 1. It is of note that 6 Phase 1 participants declined Phase 2, and 2 participants had died during Phase 1 of the study.

To enhance the representativeness of the entire sample, we also selected a new random sample. 19 of the 32 (60%) reachable and eligible people in this new sample agreed to participate.

Thus, an important accomplishment of this year was to re-consent and extend the sample for the new phase of work. Phase 2 will follow 82 people out of 117 people contacted, with an overall acceptance rate of 70%.

Five people in the sample died between the 24 and 30 month post-discharge observation. There have been no additional deaths in the sample. Thus, we are currently following 75 people. Five people have completed the study, that is, they are more than four-years post-discharge. Seventy people remain in the study.

3) Continued data collection.

Phase 1 procedures are continued in Phase 2. Standardized assessments are completed every six months, in between visits for standardized assessments we check in with participants. These check-in visits also allow us to conduct longer, more in-depth interviews regarding participants' adjustment to

their new living places and their satisfaction with services. In Phase 2, these interviews are focusing on the participants' views of "home", and how their residences meet their needs. All assessments are carried out in the participants' residences; it is common that we visit multiple times to complete a single assessment.

Data collection for both phases of the study is reported below. About two thirds of people we are following participate in any given time point, and recruiting the full sample requires several months, thus, we conducted between 40 and 50 standardized assessments at each major time point during Phase 1, and we anticipate conducted between 50-60 standardized assessments at each major time point during Phase 2.

The number of completed standardized assessments for Phase 1 and 2 is shown in the Table below. In addition to these, we have completed 248 check-ins across the entire study (128 during Phase 2), and 41 in-depth interviews completed during Phase 1, as well as the 24 completed last year mentioned above.

Number of standardized assessments completed at each time point for Phase 1 and Phase 2

	Hosp	3 mo	6 mo	12 mo	18 mo	24 mo	30 mo	36 mo	42 mo	48 mo
N	21	13	41	51	49	57	59	36	15	5
	DONE	DONE	DONE	DONE	DONE	DONE	DONE	UNDERWAY	UNDERWAY	UNDERWAY