

October 30, 2023

To the Green Mountain Care Board:

I am writing to you in response to your request for comment about hospital experiences in Vermont. I live in St Albans and will write about my adult daughter's experience two years ago at the University of Vermont Medical Center. She is in her early 50s and has had many medical and mental health issues over the years requiring hospitalizations in different specialty floors; the last two were by far the worst.

The Admission Process

I will begin with the problem of being admitted to the hospital. What a nightmare! In the past, a primary care doctor or specialist would arrange for the admission at a certain date and time and we would go to the admissions desk and it would be taken care of quickly and efficiently. Not so today. Community doctors and specialist DO NOT have admitting privileges. * A patient with a known complaint for which hospitalization is considered necessary by a board certified doctor is advised to go to the emergency room to be admitted. The emergency room itself looks like a casting call for *Les Miserables* and one rightfully has concerns about contagious elements, etc. A wait time of five to seven hours is not unusual and in fact, during the time we are speaking of, the nightly news repeatedly was warning of even longer times. Eventually you are shown into a small room (after passing people on gurneys and hospital beds in the hall) and medical personal start an evaluation that itself will take hours as tests are ordered, administered and results viewed. Then, if you are extremely lucky, you will be admitted for the purpose that the primary care physician advised.**

Why such a procedure? The cynic in me says it is to make money for the hospital. My limited understanding of the situation is that anything that is done in the Emergency Room costs more than in the Out-Patient Labs, and the public is constantly being admonished not to use the Emergency Room in place of a private physician. Northwestern Medical Center in St Albans has a new well staffed Urgent Care facility that I have visited on occasion and have been extremely impressed with the quick, efficient and professional attention I received.

The Hospitalization

Before making the trek from St Albans, we had checked to make sure that there was an available bed and after seven hours our daughter was sent up to a lovely single room in the new wing of the hospital. We were very impressed with the room, the efficient layout, the friendly staff, etc. Her two outside specialists who wanted the hospitalization to confirm their diagnosis of an uncommon auto-immune disorder were able to provide continuity in her treatment***and care.

Her stay in this lovely facility was short-lived as she was transferred to one of the specialized antiquated floors. We had expressed the hope that she would go to the psych ward where her medications could be reviewed and she might receive some help for her long-standing psychiatric issues. With so many providers prescribing medications we hoped that someone would provide an overview and some clarity. Also, in the past she has found that the psychiatric nurses provide a level of care and compassion not seen on other floors of the hospital. This wish was not granted and her stay on this "medical" floor was difficult and, as is often the case, staff did not want to deal with a person with mental health issues and difficulties.

I have long believed, as a result of extensive reading on the subject, that there is a link between mental health issues and digestive issues. My daughter's digestive issues went undiagnosed for decades as it was much easier to slap a psychiatric label on them than to look for root causes. In this hospitalization the outside specialists were looking at root causes and the hospitalist was looking at behaviors that didn't fit their schedules. My daughter has to eat small amounts over a long period of time; that is not convenient for staff. When she was hospitalized she was at an extremely low weight and it was obvious that something was wrong and not amenable to a quick fix. After a very tense week, the hospitalist came up with a plan and a contract that looked like it would work to regulate her eating to meet her needs and the staffs. She signed it on a Saturday and the hospitalist called us that afternoon to say that lunch had gone well and he was modestly hopeful that they had turned the corner; he was going home, his shift was over.... Sunday morning at 9:30am, we received a call from the hospital that our daughter had been discharged from the hospital because of disruptive behavior the night before and was in a cab heading to St. Albans!

What happened? This is what I pieced together from what the hospital told me and my daughter's own account: The contract between my daughter and the staff included a provision that she would receive her meals at designated times and would have a certain amount of time to finish her tray. Saturday night she did not get a tray at 6:30 (as mandated by the contract) and by 8pm asked the nurse for it. The nurse said that there was no tray available; the kitchen was closed but she could have canned soup and crackers from their pantry for dinner. She became upset and disruptive and finally at 10pm a nurse took her down to the staff cafeteria to get something to eat. She was summarily discharged the next morning.

The Appalling Lack of Psychiatric Facilities

We were outraged, but there is no recourse and, as we all have had to do so many times over the decades, we had to patch things up and soldier on. My husband and I have just celebrated our 80th birthdays. We no longer have the strength, fortitude and resources to play the role we have had dealt us because of the mental health system in Vermont. The state hospital in Waterbury was a tremendous resource before it was shut down by the powers that be. The national rush to "de-institutionalize" was misguided and we are all living with the consequences. The community mental health centers are insufficient in their scope of offerings and not monitored for quality and compliance. There is no accountability in the system.

Years ago one of the best psychiatrists my daughter ever had told me she was going over to the developmentally disabled side of her county mental health agency as she was tired of knowing what resources her psychiatric patients needed but they were not available. In contrast, she said that the developmental side had ample resources to help their patients. How many of our homeless are on the street because of the resources we have not put into the care of the mentally ill? How many are addicts because there are not appropriate programs for them? How many people have died because a psychiatric diagnosis led to a stigma but no resources to treat it? There are no available beds when a person is in crisis; there are no longer term placements for a patient to be monitored and brought to a stable place. The state hospital was not just for "lifers" but for the person whose life has gotten out of control and who needs a respite of a few weeks or months to get back on track. Wake up Vermont! Lewiston, Maine is just a state away.....

Ann Selgin Levy

ps. I am attaching a letter that I wrote in July after we had had a particularly difficult time with our daughter. The July floods made it difficult for me to disseminate it; perhaps this is the group that needs to see it most. I am enclosing the cover note to the Governor.

*I recently learned that the doctors at the University of Vermont Medical Center' Family Center in Milton don't have admitting privileges even though the name would suggest otherwise.

**Our experience at the UVMMC was reminiscent of the treatment he mentally ill patient received in Emergency Rooms across the state when they were in crisis thirty year ago. Now the entire population is subjected to the same inefficient, uncaring and demoralizing experience when they and their physician feel they need hospitalization.

***The hospital staff was unable to insert a nasal tube to relieve pressure on her abdomen so her doctor came in on a Sunday morning to perform the procedure.