

## Disorientations

*When my ex told me to go get a prescription, he's like, "You have schizophrenia. Go get a prescription for schizophrenia." Which I've never been diagnosed with it, but he told me to go get a prescription and then they end up omitting me—is that the word? Omitting me in the hospital.*

—VERONICA, SHADY ELMS HOSPITAL, DAY 3

Flashes. They remember it in flashes. Bright lights, loud sounds, rough handling, confusion, a lack of information, forced separation from family for up to 72 hours, the possibility of unwanted injections or being placed in restraints. The experience is like no emergency room arrival they ever imagined, and it is the hardest part to remember—the intake.

On top of that, they were experiencing psychosis.

Take Amy, for example. We know Amy. She asked for help from the police instead of stepping off the overpass. When I first met Amy at Shady Elms, she had been admitted a few days earlier. She haltingly pieced together what happened upon her arrival.

AMY: Of, of course, they admitted me. I was going crazy . . .

NEELY: Mm-hmm. [*Affirmative.*]

[*Pause.*]

AMY: I—they had a camera where they had to take a picture.

NEELY: Mm-hmm. [*Affirmative.*]

AMY: And I guess it set me off and I tried to smash it, and they had to put me in four-point restraints.

NEELY: Oh.

AMY: Yeah.

[*Pause.*]

NEELY: That must have been really tough.

AMY: Um, not as tough as what was going on with me.

NEELY: Right.

AMY: Like it all needed to happen in order for me to find out. Because for some reason all these bizarre things can happen . . .

NEELY: Mm-hmm. [*Affirmative.*]

AMY: And you can still feel like you can normalize.

NEELY: Right. So, how do you—how do you feel now?

AMY: Um, it's pretty humiliating.

NEELY: Yeah.

AMY: I get nervous because I can hear some things that I could misconstrue and it makes me fearful I could start hearing those voices again. [. . .] I feel like I've forgotten a lot, but I think it's just from being in here, whatever it is . . . It is making me forget and I didn't consent to any of this.

NEELY: What could your brother and sister do next time? What would they do differently?

AMY: They could talk to me. They didn't even talk to me about anything.

Amy had trouble remembering the details of her intake, but she remembered being humiliated. She tried to avoid having her picture taken because she did not look very nice after traveling by bus and wandering the streets and this was not an image she wanted on any record. She said she overreacted, and they strapped her to a table—spread eagle—against her will. Amy was angry with her family, confused by her own behaviors—fighting with her sister, trying to smash a camera, forgetting things that had happened—afraid of having more symptoms, and dismayed that she was now being held at Shady Elms involuntarily. Later, she reflected on her experience:

AMY: One thing that does frustrate me is the whole time I was going through all of that, they never told me what was going on.

NEELY: Right.

AMY: I don't know why they do that.

NEELY: Do you think if they told you, you'd have been able to comprehend? Would it have helped to know?

AMY: No. I really don't know that it would've.

But how could she know? She never had the chance to find out.

After her intake experience, Amy struggled to accept further mental health treatment. Even though she was admitted voluntarily, when she refused medications and wanted to leave, the doctor and judge changed her status to involuntary. She tried to throw herself out of her brother's moving vehicle to avoid a follow-up visit.

In the end, however, she accepted care because she needed housing. She did not want to be homeless again. That is what got her into this mess in the first place. Her brother would not let her stay with him unless she took her antipsychotic medications and went to her follow-up appointments, and so she did.

Miranda's intake experience was similar. She did not give me the details of her hospital arrival until a few months into our interviews. When the time came, her story, like Amy's, began with a point of humiliation, as though these humiliations anchored people's fragmented memories.

*MIRANDA:* It was just scary. The "squat and cough"—that was scary. I felt that, you know, I felt like I didn't own my body, like my body wasn't mine.

*NEELY:* Okay . . . were they doing that with every person that was brought in?

*MIRANDA:* I don't know. I mean, I only experienced mine, I don't know if they did it for everybody. But they did it for me, you know? And I understand that they have to do that for safety reasons. But, ideally, they would trust you. [. . .] Because what happened was, I didn't really even know what was going on the whole time. So, if somebody let you know, "You're here because of this" or "You're here because of . . . you're going to have this happen to you because . . ." You know? Because the whole time I was like, "Oh, I don't know what's happening . . ." It was really disorienting.

Later in the interview, I asked Miranda if she thought people's hospitalization experiences influenced their treatment decisions.

*NEELY:* Do you think the kind of treatment that, you know, you received upon getting to a hospital influences a lot of people's decisions about whether to go back or not?

*MIRANDA:* Oh, yeah. Definitely. I was brought to Shady Elms by cops . . . I wanted to go to therapy . . . I don't like authority figures and I think a lot of people don't like authority figures, period. I think that added to my hostility that I was brought by cops. And I think that I wouldn't have sought psychiatrists; I would have sought out therapy. Because I almost was at the breaking point where—well, I *was* at the breaking point where I needed help. And I think that I, if I didn't go through my manic phase, I would have gone to therapy. But I don't know if I would have gone to a hospital.

*NEELY:* Right. So, in an ideal universe, definitely that's not the treatment you get.

*[Miranda and Neely laughing.]*

*MIRANDA:* No. No, yeah.

Intake was much the same for everyone in our study. A young person came to the hospital through the front or back door and then was separated from the world as well as their families. Once inside, they were escorted to a room by police who searched them, photographed them, and took their personal belongings—phones, valuables, clothes. If they resisted, they were put in four-point leather restraints used to strap their wrists and ankles to a gurney or chair.

Most were given a liquid concoction to calm down—a “Shady Elms cocktail” as the local police called it—of liquid Haldol (an antipsychotic), Benadryl, and Ativan (an anxiolytic). A nurse told me that the cocktail enabled the patients to sleep off whatever had brought them in. Those who resisted the paper cup typically received an injection.

As the sedatives took effect, the patients were laid on dark-blue plastic recliners in a room the size of a junior high school gymnasium. When they awoke, typically quite groggy, they continued the intake process by going into a small, dim, windowless room for an in-depth interview with a social worker who typed notes furiously into a computer. People like to compare mental health concerns to having diabetes or a broken bone, but this was not anyone’s typical visit to the emergency room. The psychiatric emergency visit is unlike anything else.

I am not saying that Amy and Miranda did not need help. They did need help and they knew it at the time, and they knew it when I talked to them after their intake, whether that was days or months later. What I am saying is that they—and many others—did not get the help they were seeking. Instead, their experiences in the hospital were harmful to their moral agency. They had been treated like a “bad” person—police escort, handcuffs, mugshot-type photos, squatting and coughing to check for drugs, put in four-point restraints, not informed of their situation, forced to take medication—which was dehumanizing and had a lasting impact on their perception of care. And even beyond the hospital, being a person who had experienced a psychiatric hospitalization threatened their perception—and others’ perceptions—that they were good people. Damage control was not an option. It was almost impossible for them to edit this part of their life stories. Their initial hospitalizations constituted a rupture in their life narratives that would be difficult to repair.<sup>1</sup>

. . .

At Shady Elms, I was able to watch most of this happening from what I came to think of as “Central Control.” Central Control was a panopticon designed to render all patients visible while protecting staff from danger. The staff enclosure was bright, but the patient area was dark—lit by eerie, dim, blue lights. Beyond the glass, up to eighty people at a time lay prone on rolling plastic royal-blue recliners. Men rested on one side, women on the other, but the two sides had no barrier between them. The people I saw lying there represented a range of ages, socioeconomic backgrounds, and cultural orientations. Most were asleep—sedated—under a thin blanket.

The staff area was segregated, enclosed by a wall of bulletproof glass with little windows the nurses could slide up and down a few inches to talk to patients. Overhead, several large, soundless, closed-circuit television screens flashed images of often-handcuffed new admissions undergoing those first interactions—police searches, intake photos, restraints, injections. Phones rang while staff tapped away

at a dozen or so computers, looking up patients' records. Doctors in white coats flipped through patients' paper charts in binders. The more frequently a person visited, the larger their chart. The youths in my study usually had near-empty binders waiting to be filled.

A few weeks after his arrest for trying to "bless" people in line at Starbucks, Gideon offered a few thoughts about his experience. "The funny thing was the police arrested me and took me to Shady Elms and told me to lay down on a rest table, tried to calm me down or whatever. I know, 'Why you put a handcuff on me and tell me you're not arresting me? What kind of sick joke is that?' 'It's okay, I'm punching you, but you don't feel anything.' [. . .] I was like, 'No.' I just kept quiet."

Keeping quiet and not resisting, Gideon had learned, helped keep him safe.

Sometimes people woke up agitated and started causing trouble. The psychiatric technicians—dressed in distinctive black scrubs—would handle them as quickly as possible, but occasionally, workers were punched or bitten, or patients were knocked over by other patients. It was a tense environment. I feared for my own well-being more than once. This was hard, unpredictable, and dangerous work. I understood why many staff hardened themselves against empathizing much with their patients; they always had to be on guard for the unexpected. The other patients, especially the young ones I worked with, had no idea how to interpret or navigate this volatile environment. For them, it was incredibly scary.

One morning early on in my fieldwork, I had just used my badge to open the first of two sets of doors that led to the outside courtyard when a patient burst through the second door. I was supposed to pull the door closed behind me to keep anyone from getting out, but I was so startled and frightened that I did not think to close myself into a small space with a large, frantic man in paper-thin scrubs. I flattened myself out of the way as he burst past me across the enclosed courtyard and tried to climb the only wall that provided any access to the outside. Of course, it was too tall for anyone to climb, and even if he made it over the wall, the police parking bay was on the other side. I watched as two psychiatric technicians—large men dressed in black scrubs—pulled him off the wall and enacted what they called a "takedown," which meant restraining him until an injection of sedatives could be administered.

Shaken, I considered going home for the day. However, this was early in my fieldwork, and I had a feeling this experience was like falling off a horse. If I left, I might not be able to get over the fear. So, instead, I took a deep breath and reentered. It reminded me, though, that patients saw these kinds of things all the time—an agitated person, a threatening encounter—but unlike me, they could not choose to go home. They had to stay. While I could hide behind the nurses' desk or move from one ward to another, quickly putting a locked door or some bulletproof glass between myself and a stranger who rushed at me, the patients had no such luxury. They were constantly exposed to the possibility of danger.

Miranda talked to me about this. She said that at one point she felt like Winona Ryder in the movie *Girl, Interrupted* when she realized she was at a mental institution, but she did not know why.<sup>2</sup>

That was really scary. I mean, anybody—you don't know what's wrong with them. Or, you know, they could have done something more severe than what I'd done. I'd threatened my dad. But it's just the fact that everybody was in there and you don't know what they did. You know? It was just kind of like—they didn't have a—I don't know, *screening* or something. But I guess in an ideal world, people with violent tendencies would be separated from the ones who don't have violent tendencies. I mean, but, you know, I threatened my dad, so I could have been put in with people who had violent tendencies. I mean, all I did was threaten him. Well, that sounds—that almost sounds like I'm dismissing it, but . . . you know?

Miranda wanted to be separated from the “bad” people, and she was struggling to distinguish herself from them. We can see her moral agency coming into question. Is she one of the people that others need to avoid? Of course, she also wanted to avoid dangerous people—who wouldn't?

Miranda's mother, Angela, told me that something happened to Miranda in Shady Elms. The first night she talked to her, Miranda said some strange things.

“It was just a big mess,” Angela sighed. She demanded that they transfer Miranda to a private hospital, using her mother's insurance. Angela was allowed to watch her exit from the ambulance at her new location, because she had a medical license, and she could see that she had a hickey on her neck.

“That just baffled me,” she said. “I just couldn't believe what was happening.” Angela could not imagine why medical professionals would put Miranda on suicide and homicide watch in a room with other people who could take advantage of her vulnerable state.

During another visit, I stood listening to a nurse talk to patients who came up to the Central Control window. She gave them psychiatric medications in a little paper cup to help them stay calm while they waited. She told me that the initial intake area was hardest on the “first-timers” because they woke up in a room of people and had no clue where they were. They always looked the most freaked out.

“Look!” She smiled. “Here comes one now.”

A young, white man whom I came to know as Jack shuffled up to the window. Jack was the first first-timer I met, and it was heartbreaking. He was crying, wiping his tears on his sleeve as he approached. The nurse slid the window open, and his voice cracked as he asked, “Did I die? Am I dead? Am I in Hell?”

“No, you are not dead. You are in a hospital, and you need to go lay back down on your chair and wait,” the nurse responded.

“Please! What happened?” He begged. As mentioned before, Jack could not remember. A lot of young people could not remember: they had some amnesia

about events surrounding their psychotic break. It was not clear to me if it was the Shady Elms cocktail or the effect of potential dissociation during their episode for psychological protection or something else entirely, but it was common all the same. Sometimes their memories came back, and sometimes they did not.

Jack and the nurse went back and forth a few more times, him hobbling up to the nurse's station, her telling him to sit back down. Finally, she placed another pill in a paper cup and pushed it through the slot.

"We will wake you up when the doctor comes," she insisted. Jack nodded and sobbed.

"Can I go and sit with him if that's okay with him?" I asked.

The nurse agreed and asked me to take him away from the recliners and talk to him in a chair on the perimeter so that we did not disrupt the other patients.

Jack was eager to talk.

I explained that we were at a psychiatric emergency room called Shady Elms where the doctors would see him and help him know the next best steps to help him manage his mental health. We looked over the patients' bill of rights posted on the wall behind us.

He had many questions.

"What time is it? What day is it? Where am I in Texas?"

Jack was not from Dallas. I showed him our location on Google Maps on my phone.

He then asked to use my phone, and I regretfully said I did not think that was an option. Later staff confirmed that patients should not be allowed to use my phone, and near the end of our study they banned cell phone use around the patients completely to protect confidentiality, though in general we had only been using them to record interviews.

Jack asked me where his phone went, and I told him I did not know, but I was sure he would get it back when he was discharged. We asked the nurse if he could make a phone call, and she pointed to an unmarked gray phone on one of the walls for local calls. But the extra pill made Jack sleepy. Maybe he would wait until he woke up again, he said. He had stopped crying, and I offered to tuck him into his chair. He nodded and lay down on the blue recliner and I placed his blanket over him. He tucked it under his chin and smiled.

"Thank you," he said, reminding me of a child.

Jack went on to accept medication and needed very little further mental health treatment. He was one of the few young people in my study who was hospitalized only once, to my knowledge. But Jack had a large family who loved him and a lot of resources. They circled around him and helped preserve his moral agency through this difficult time while also making sure he followed medical advice.

Amy, Corrina, and Miranda also eventually accepted mental health care for various reasons—housing, familial pressures, a way to move forward. Ariana was different—she refused care. On the day I met Ariana, a nurse told me to look for a first-timer in the "secondary" emergency room. This was a smaller, very dim,

yellow-lit space where people who had been through the intake interview and thus “processed” then waited for up to 72 hours to see a doctor. At that point, they were either admitted (voluntarily or involuntarily), transferred to another inpatient facility, or discharged. Once there, I paused in another glassed-in nurses’ station—a miniature version of the Control Center with a few chairs and a computer—to ask for help identifying Ariana.<sup>3</sup>

“Oh, *her*.” A nurse pointed at a young Latina in another recliner. “Good luck with her. She’s not talking. She will just think you’re part of ‘The Conspiracy.’” A hand gesture of air quotes communicated how silly that idea seemed.

“She looks asleep,” I noted.

“Oh, she’s not asleep,” another nurse said. “She hasn’t slept since she came in two days ago. She’s been in four-points twice already.”

Three months later, Ariana told me how she had ended up being restrained and given injections of sedatives without permission.

I wouldn’t open my eyes. I remember that. I wouldn’t open my eyes. And I thought it was the end of the world, blah blah blah, if I opened my eyes they would kill me, blah blah blah. And so they’ll sedate me. And, apparently, they sedated me twice. I just remember one time. I was acting crazy. And they’re like, “Okay, if you act crazy, they’re going to take you up there because you’re acting crazy.” I know I would never try to hurt nobody, I just—they [her voices] don’t want to open my eyes. I’m like, “Don’t open my eyes!” I’m like, “Let me go! Let me go!”

When I saw Ariana’s eyes flutter open, I scanned my badge again and entered the smaller patient area: here the recliners were packed side by side, and there was no gendered segregation that I could see. The Syfy Channel was playing on all the televisions but was mercifully on mute. Even so, it was showing bizarre scenes of witches and demons. It seemed like an odd choice.

I asked Ariana if I could sit with her, and she nodded yes. As soon as I sat down, though, she leaned in. Our heads were too close. She looked me straight in the eyes, our noses an inch or two apart. I felt uneasy.

A few days later, during a more formal interview, Ariana told the interviewer that she had a language barrier—English was her second language—and a hearing problem that made it hard to advocate for herself. She said:

*ARIANA:* I don’t ask questions because I can’t hear, and if I can’t hear you, then I’d just rather not. I try to get close, and people take it the wrong way. You have to talk loud enough so I can hear you and I feel intimidated by my hearing.

*INTERVIEWER:* Right. Have you tried telling people that you can’t hear?

*ARIANA:* I tell them, but it’s like they don’t listen.

I felt badly when I learned about her communication concerns, because I had misinterpreted her proximity when we met. Her closeness made me uncomfortable. But at the time, I wanted to connect with her, so I forced myself to stay.

“Are you the chaplain?” she asked me.

“No, I am a volunteer here. Would you like to talk?” I showed her my volunteer badge.

Ariana pressed my arm with her hand. “I gave blood three times!”

“Oh, that’s nice.”

“In high school, like a charity thing.”

I nodded.

“And I did pretty well in high school.”

I nodded again. Looking back, now I can see that Ariana was trying to express some moral agency and signal to me that she was a “good” person even in this difficult place, but at the time I was too busy worrying about her distress and monitoring our physical proximity to notice. She fidgeted restlessly.

“Stop nodding!” She snapped. “Why are you nodding?”

“I am sorry,” I said, confused that my body language had offended her.

She exhaled heavily into my face. “See?” She asked. “It’s bad, right? It’s bad breath. It’s Ebeullah. We are all going to die of Ebeullah, which is in our lungs and it’s spread through our bad breath.”

I struggled not to nod my head again while Ariana continued exhaling heavily into my face. Her breath was terrible. Had she been offered a toothbrush?

To break our overwhelming proximity, I noted that the clock on the wall had stopped, and I pulled out my phone to check the time. Like Jack, Ariana immediately asked to use my phone.

“I want to know what’s happening out there,” she said in frustration.

I did not see a phone in the room, but I assured her the outside world was well and told her it was St. Patrick’s Day.

“It is?” Another patient called to me across the dim space, suddenly creating a rare sense of community in a space where most people struggled alone.

“Really?” Another asked.

“Yes, it’s March 17. St. Patrick’s Day.”

Ariana was still in her street clothes; she said she felt dirty. She was waiting for a shower, but there was only one, with an attendant who kept watch from the other side of the curtain. She rubbed her arms persistently, which she said ached where she had been restrained and injected with sedatives. She told me she was very tired. I suggested she rest.

Her posture softened. “Will you watch over me?” She whispered. “I am afraid, but I won’t be afraid if you stay with me.”

“Okay,” I said, feeling maternal. “I can’t promise I will be here when you wake up, though.”

My mind raced. I thought of the late hour, my own young daughters, relieving the nanny, making dinner. But, as with Jack, I also felt her powerful need for someone benevolent to share space with her.

“I will just feel better if you are here,” she said. Ariana needed to feel safe. I felt that I could offer this to her, at least.

She reclined her chair and closed her eyes. I tried to relax, but it was pointless. A few minutes later, Ariana was awake again, trying to explain about Ebeullah and how she was going to save the world, all the while exhaling long, warm, foul sighs into my face. She kept rubbing her sore arm, asking me about my religious beliefs, trying to see if we shared ideas about the Book of Revelation. Again, I later realized this may have been an attempt to establish herself as a “good” person and find some kind of common ethical ground, but in the moment, it was just tiring. I tried to be soothing and encourage her to relax, but she moaned, “But relaxing makes the voices louder!”

When the real chaplain came, I was greatly relieved. It is difficult to be present with people in the throes of psychosis. It can go on for days if they cannot sleep. Sofia’s mom noted how hard it had been to keep watch over her for days when she could not sleep. I could imagine.

Ariana ended up being admitted to the hospital. Months later, she decided to completely refuse mental health care. I share more of her story in chapter 5, but one piece she reflected on when explaining that decision was this early hospitalization. She explained: “You’re so scared. You don’t know what’s going on because you don’t understand what’s going on with you. And it’s like, What the heck? It feels degrading and aggravating.”

. . .

Once they were processed through intake, patients were either admitted into the hospital with private insurance or—if they lacked coverage and had to use the regionally offered public mental health insurance<sup>4</sup>—it seemed to my team that they were then sent to the local state hospital. We were not able to get a clear answer about this during fieldwork, and when I tried to check retroactively as this book was going to press, no one could recall the policy in effect from 2014 to 2017, and the regional public insurance was no longer offered. However, during our fieldwork, a transfer to the state hospital seemed to happen consistently to people without private insurance and did not seem to happen to those with private coverage.

During our initial interview, only 9 participants claimed to have private insurance out of the 27 who answered the question; 10 had regional insurance, 1 had Medicaid, and 7 had no insurance. Miranda, Jack, and Corrina all had private mental health coverage through their parents. They never went to the state hospital. Amy did not have insurance, but her brother Robert panicked and purchased private insurance when he heard she might be sent to the state hospital if she had only public insurance. His alleged conversation with hospital staff was the closest we got to confirmation of this pattern during the study.

“They’re like, ‘We’re gonna send her to [the state hospital],’” he explained. “That was the breaking point. I said, ‘No, I’ll pay. I’ll pay. She’s not . . . she’s not going there. She’s worth this,’ I would tell the doctors. I begged for people to help her to get her out of that ER room.” It turned out that Robert and Amy’s grandmother had died in a state hospital after being hospitalized for schizophrenia. Robert could not bear to think of the same thing happening to Amy.

Sofia, James, Ariana, Latoya (mentioned below), and Michael all lacked insurance, and all went on to the state hospital about an hour’s drive from Shady Elms. It could be that their families authorized it, but that’s clear only in Michael’s case, which I share below. Sofia’s family definitely did not authorize the transfer, but Sofia may have agreed and cannot recall doing so. We don’t have access to that information, and people were often confused about what happened. We do know that many people without private insurance went to the state hospital for a nearly month-long or longer stay.

The state hospital, built in 1885 in the old asylum style, consisted of a crumbling set of red-brick buildings with white columns—some boarded up and condemned, others still open for business.<sup>5</sup> One news report described one of the condemned buildings: “The roof leaks, stalactites and stalagmites grow on the second story, and yellow paint is peeling off the walls . . . Young patients [there . . .] walk past the building every day on their way from their dorm to their school.”<sup>6</sup>

Every member of my research team, me included, felt haunted by the place. It was just spooky. There was even an old patient cemetery onsite. Visitor check-in, which my research team used regularly to visit young people in the study, was in a portable building. Visitors could meet for an hour or so each day with their loved one at a table there.

The people the team followed who were transferred to the state hospital were typically held for around 30 days total (including their time at Shady Elms) and we could only guess that this was to meet government readmissions requirements designed to “improve health care quality, improve the health of the US population, and reduce the costs of health care.”<sup>7</sup> To meet these government standards for medical reimbursement, a patient could not be readmitted to the emergency room within 30 days of their last service. If they were, it counted against the quality metrics being used to evaluate the hospitals for Medicaid and Medicare reimbursement by the federal Centers for Medicare and Medicaid Services. To avoid penalties for the entire hospital in the event of excess readmissions, people who seemed as if they might be readmitted during that time had to be sent somewhere to make sure they were not. They needed to stay “admitted.” Shady Elms could not really hold people that long, so they were sent to the state hospital. These rules apply to any psychiatric inpatient program that bills Medicaid or Medicare in the United States, and I have visited psychiatrists who ran psychiatric wards on the East Coast who have shared that their hospitals had similar practices.

However, a 30-day total psychiatric inpatient admission was highly disruptive for a young person. Coworkers, friends, roommates, teachers, and neighbors take notice when a young person is gone for an entire month. For first-timers, or any young person trying to keep their lives on track, this disruption was devastating, and it seemed to disproportionately affect the young people in our study who needed public insurance to cover the cost of mental health care.

Sofia remembered experiences at Shady Elms and then at the state hospital in an interview about four months after the research team met her. Her mom, Maria, had brought her to the county hospital after she noticed her declining college performance, but also, as revealed earlier, because Sofia refused to sleep inside.

*SOFIA:* I just remember writing down information, and they wouldn't tell me anything. So I did not like it. I think that if I would have spoken with the doctor there, I wouldn't have gone to [the state hospital]. I think I could have been discharged immediately. I think I wouldn't have to have gone through all that, but I really don't remember what they did to me. I just remember like being at Shady Elms and then the next day just waking up and being at [the state hospital], so I don't remember that.

*INTERVIEWER:* Really?

*SOFIA:* I don't remember, that's why I don't know if they gave me some kind of injection and put me down to sleep or what they did. But I was perfectly fine in Shady Elms and then when I got to [the state hospital] I just remember having to speak with an attorney and having to sign the paper, and also signing to be part of a study, and that's all I remember when they took me to [the state hospital] but I don't remember.

*MARIA [in Spanish]:* Yeah, I talked to the nurse. The nurse she told me, "She's okay, she speaks, she's okay, but she needs to move to [the state hospital]." I said, "Why?" "Because she needs to stay there, because here is only for emergency—for one day, two days."

*INTERVIEWER:* Did you want her to go there?

*MARIA:* And then I go see her the next day, but I don't see her. She said, "You need to wait 42 or 72 hours," or something like that [. . .] I had to go to a pastor that was there, I had to wait like three or four hours so that he could go in for me and I could know how my daughter was.

*SOFIA:* Oh, I remember him talking to me once.

*MARIA:* Yes, it was him. I had to go. I don't know how I thought about that, but I needed to know, so I saw that there was a pastor. They told me at what time he would be there. I waited for him. So then I went with him, and through him I found out about her.

*INTERVIEWER:* That she was okay, because that was the only thing you wanted, to know that she was okay . . .

MARIA: In Shady Elms, they wouldn't let me at all. But the good thing was that they took her quickly over there.

SOFIA: They took me that same day.

MARIA: Yes, 42 hours had to pass before they could tell me anything.

INTERVIEWER: Why 42 hours?

MARIA: Because they had to do paperwork and I don't know what else, supposedly. I don't know. Very strict.

Luckily, Sofia's mom had permission to ask about her, because Sofia had consented to sharing medical information with her. Maria went to visit her every day despite having to leave her other two daughters, the cost of gas, the long distance from the city, and her two jobs cleaning houses. Unfortunately, because she was at the state hospital for so long, Sofia lost her college scholarship.

"I think they did their best to help me out," Sofia reflected, "but I really wish I wouldn't have stayed there for so long. 'Cause it definitely does—it marks you. Something that's hard to, I don't know, to just kind of get over."

Looking back, Sofia decided to use mental health care because she was very afraid of being sent back to the hospital. Sofia and her mom explained:

MARIA [*in Spanish*]: Yes, she is still with the fear of "it's going to happen again," and it's not something easy. Just by simply being in the hospital seeing the other patients, because when I would go see her, I would see her well compared to the others, and I myself would become traumatized from being there. From seeing the other people, because there is a lot of sick people. And she was not sick, but she was hearing everything and so she was getting traumatized. She became traumatized there.

INTERVIEWER: It like adds on to the fear of going back and having those hard thoughts on top of all that.

MARIA: Over everything it was the fear of being there.

INTERVIEWER: Wow, how tough. And for you, was it the same fear of being like that?

SOFIA: Yes, of going back.

MARIA: Because she couldn't sleep, from the noise, because they would curse a lot. They would say a lot of nonsense. It's obvious that it is a hospital, but I think she couldn't be in a hospital like that.

. . .

Others, sometimes because they were confused or angry with their parents, refused to give permission for families to receive information. This may have also prevented family members from advocating for them or stepping in with private insurance as Robert had done for Amy. Miranda's mother, Angela, could not get any information about her, because Miranda had not consented to letting her mother hear more about her.



FIGURE 4. "The Hospital: The hallway bathroom" by Lauren Ann Villarreal. The artist wrote the author in an email: "It is about my time in the mental hospital. As on the paper, there were no mirrors in the facilities, we had to use our imaginations. While I was there, I saw myself as already dead. The space was so traumatic, I was at the lowest place of my life. Not being able to see my reflection made me feel like I didn't exist anymore. Being there made me feel like the only way out, both from the hospital and my pain, was dying." *Reproduced with permission of the artist.*

“She thought I was the enemy. She wasn’t allowing anyone to talk to me. So it was very difficult—very, very difficult. I even tried to get guardianship over her because I didn’t know what was going to happen. How can they let her sign papers in this state of mind? How? I mean, I don’t understand that.”

Michael’s family also had difficulty gaining information about his well-being once he was at Shady Elms. They had called the police when Michael tried to harm Liza’s daughter, who (as related earlier) he thought was a demon. During an interview six months later with Liza and Michael, they explained what happened.

*LIZA:* I called up there multiple times, and they wouldn’t let me talk to anybody, but it was Michael who wouldn’t let us know what was going on . . . I thought, if he just signed that paper for—what if someone can see what they were doing to him in the first place, then we can be like, “No, he don’t take this [medicine],” but since he did his legal guardian himself, and he wasn’t well, they could really do whatever they wanted to do, because—

*MICHAEL:* I think the court . . . like, the judge, like, ordered it, for me to take it, so that’s why they forced me to take it.

*INTERVIEWER:* Right.

*MICHAEL:* I don’t know.

The judge eventually declared Michael incompetent, admitted him involuntarily, and contacted his mother. He asked her for permission to send Michael to the state hospital. She agreed.

Liza said they regretted it right away. “We thought it was something nice and it will help. We didn’t know it was like—what I knew was crazy.” She described how they had pictured it: like a place on television, a place to rest and relax, a place with a view and natural beauty. They clearly had no experience with this sort of institution.

Then, Liza confided in a friend.

*LIZA:* When I said, “You know what, my brother is in [state hospital],” I told my friend, and she was like, “Where?” “In [state hospital].” And she is like, “Go get him out of that place.” She told me, “Go get him out.”

*INTERVIEWER:* Wow.

*LIZA:* She was like, “*People*, like—what?” The reaction—it was a negative reaction. You know? It was bad.

Unfortunately, Michael’s mother had already signed the papers. She had tried to talk to Michael, but he was not making any sense. He had not taken any medications. She thought the hospital would help.

Later, Michael said, “I think you guys kinda got to understand, like, at that time I wasn’t in the right mind. I was like thinking my family was like secret organ— organizations.”

Michael was confused. His family was confused. People did not have the right information. It was hard to make good decisions about treatment. Options were limited by insurance and the cost of private care.

Other young people were cut off from their families. Some were not clear about where their families were, and their families did not visit them. One Latina who did not follow up with my team after she left the hospital claimed: “The major challenge I am facing is not actually being in my family on a daily basis and saying that they’re with me and knowing that I’m not crazy.”

Another young Latino shared in Spanish: “I am simply waiting until I finish my imprisonment here and that I can go back to see my brothers. I’m happy to go start a new chapter in my aunt’s apartment and begin a new chapter with them without fighting and without lying, getting along well with everybody.”

“But have you been comfortable here?” a member of my team asked.

“Kind of. Not very well because I haven’t slept. I have not been at peace because I am surrounded with people that are not my family, people who are white, they are Black, I don’t know what type of problems they have about my culture. I don’t know what kind of problems they have, what else they can add on to my case.”

He also wanted to find the staff members in authority: “Because the ones that know about one are the ones that know more: when the time comes for one to leave, to make decisions about going outside, being able to go to the park, being able to go eat lunch, or being able to go anywhere else with their authority. Because without their authority we are just whatever. We are all the same. We are all like mosquitoes.”

Patients with their own children faced additional challenges. Among the young people in my study, 10 were parents of small children and 7 of those self-identified as Latino—2 fathers and 5 mothers. The others were 1 African American parent, 1 South Asian parent, and 1 white parent.<sup>8</sup>

One young, hijab-wearing woman I met in the hospital, Haniya, was a first-generation immigrant from South Asia. Haniya missed her mother, whom she had not seen in a couple of years. She was hearing voices and felt that “everyone is reading my mind and I feel very ashamed of it. I think something or I do something, and my body sends a very wrong message.” She had told the intake nurses that she heard voices telling her to harm her children and the Department of Family Services had become involved out of concern for her children’s welfare. Haniya was pregnant and desperately wanted to see her two young children and husband. She stayed at Shady Elms for three weeks (she had private insurance), but the research team was not able to follow up with her after she was discharged home.

A young African American woman, Latoya, had also been sent from Shady Elms to the state hospital when we followed up with her. Latoya stayed there for at least six months, the length of our follow-up time with her. During one visit, she told the interviewer that she thought her stay had been extended when she became

upset at having to leave her daughter at the end of a visit. Latoya lashed out verbally at another patient then shoved her out of her way.

“I was angry ’cause I had to leave, and she [the daughter] was crying and screaming. And I just seen her outside the window. My mom stood there outside the window [holding her daughter]. And I was standing inside and [the nurse] was just standing there. And I was like, Just walk off, just walk off. I was just mad. I was like, ‘My baby is leaving and she don’t want to go.’” Latoya said she tried to explain her behavior to the doctor, but he said she had to stay at the hospital longer for acting out against others. Latoya felt he had dismissed her pleas.

“They can do anything they want to do to you in a crazy home, am I right?” Latoya observed. “Anything they want. If you say anything, you’re crazy.” After a six-month stay at the state hospital, Latoya surely knew better than me.

Another young woman, Lucia, had a three-week-old infant whom she was not allowed to see. Her family had found her wandering outside in the middle of the night carrying her naked newborn. She refused to go home or let them take her child. Her mother called the police for help, and she was hospitalized at Shady Elms with postpartum psychosis. Lucia’s breasts visibly leaked milk during our early visits, and she was not offered a pump but was instead advised to let her milk dry up since she would not be able to breastfeed due to her medications. She cried for weeks, which did not help her in ending her confinement. It took her weeks to get back to her child. Research shows that incarcerated mothers experience a sense of loss; separation from their children also seemed painful for mothers in long-term inpatient care.<sup>9</sup>

. . .

Separated from their loved ones, feeling embarrassed and ashamed for events they had trouble remembering, lacking their cell phones, and denied basic information ranging from the time, location, and date to how to use the public phone and what they were even doing in the hospital and for how long, it is no wonder that many young people felt extremely disoriented during their early hospitalization. Ideally, this first exposure to care would be one that helped a person orient to a future of seeking out mental health support for safety, empowerment, and belonging with others who understood them, but most young people I engaged with did not have that experience the first time they accessed mental health care in these emergency circumstances.

Instead, many felt that they had somehow been placed in the wrong environment. Several seemed to be making a concentrated effort to distinguish themselves from the “bad” people around them, such as the people Maria felt had traumatized her and Sofia. The young people the research team talked with emphasized that they were not on drugs, or stupid, or trying to scam the system and get a free place to stay like some of the more experienced mental health service users they met in the hospital. Many also insisted that they were not “crazy.”

As Veronica, whose sister dropped her off (chapter 3) said, “There are people here that are supposed to be here. People here who actually have drinking and alcohol and drug problems, and psychos. [. . .] I’m put in here because, not because I’m crazy or because I’m . . . but because I’m different.”

Gideon, the young man who tried to heal people in Starbuck’s, felt similarly. He had never used alcohol or drugs. Other patients teased him in the Narcotics Anonymous and Alcoholics Anonymous groups he attended at Shady Elms for never having tried anything. “Being brought here is like a worst nightmare. I try my best to always stay clean and always be clean. I have Black friends drinking alcohol and everything. I’d just find an excuse.” This frustrated him. “Yeah, that’s why I’m angry. [. . .] I have nothing wrong with me. I’m just fine.”

“Do you feel fine?” I asked.

“Completely fine, trust me. I’m even better than the so-called normal people out there,” Gideon replied.

Sage, a young African American woman whose story is fleshed out more in chapter 6, was an inpatient at Shady Elms for the longest period of anyone in our study—perhaps because she had private insurance through her parents (making her a high-paying client for the hospital) and refused medication. She pointed to her social media feed as evidence of her social worth.

“I have Instagram, and you can just do your research because I know people think I am crazy, but I am really not, and you will see. You will be able to tell how I really am. [. . .] I mean, people judge a book by its cover; people think I don’t have a brain, I’m just retarded, and I look funny, but no. I have more of a brain than a lot of people.”

Later, she added, “I don’t think this facility is logical, because I’m wasting—it’s expensive to stay here and I’m wasting my time. I could be doing my college. I am laying in a bed because I don’t think I should interact with some of the people because they have—we’re on different levels. It’s like they actually need help. And, honestly, I don’t think I need help.”

Markus, the young Black man introduced in chapter 2 who was struggling with psychosis symptoms and who would go on to refuse care, also felt he did not see people who were like him in the hospital.

*MARKUS:* When I was in that hospital, I didn’t really meet people like me; I met people, either they weren’t in a school, or they weren’t in a university, or they were disadvantaged in some sort of way. I don’t know. I felt like there was no one around who had an experience similar to what I went through.

*INTERVIEWER:* Okay. So it didn’t seem like that was the right place for you, or do you think?

*MARKUS:* Not at all, I didn’t think I needed to be there, you know. The workers at the hospital tell me, “I don’t think you even need to be here.”

The young people were looking for others who looked like them, who had similar experiences, who were getting help and getting better and moving on. Those connections would have helped them make sense of their life stories. Instead, they found themselves mixed in with the people they perceived to be addicts, “psychos,” and people who they felt were just trying to “get things for free.”

Keep in mind that while my research team was meeting with young people with many things in common, they rarely came across other young first-timers. None of our participants got to know each other (or even met, to our knowledge), in the hospital or elsewhere. They were not being oriented to a new community of supportive young people who had been through similar events. Instead, people who had already been disoriented by the symptoms and the people around them were being persistently further disoriented—from their loved ones, their everyday lives and identities, and their sense that they could be a moral agent—a “good” and competent future adult. Their hospitalizations offered a sustained assault on their sense of personal well-being and potential. This is not unusual: most individuals who use emergency departments for mental health care view their experiences as negative.<sup>10</sup>

This is not to say that people who provide mental health emergency services are bad people. Most were trying hard to understand and serve the people on their caseload. The staff the research team interacted with informally had useful insights into the injustices people experienced in the hospital and the mental health system. However, in this emergency setting, things moved very quickly. Patients were unpredictable. The staff worked amid a continual fear of danger and a sense that their hypervigilance and enforcement of firm social, physical, and emotional boundaries were imperative.

Mental health workers with their own traumatic histories may have been especially triggered by this setting. I know it was highly triggering for my research team, something each of us struggled with and, over time, talked about in team meetings or sometimes on our way to or from our paired research visits. I also advised everyone on the team to see a therapist when they joined the team so they would have a neutral person to talk to, as well—a service partially covered by SMU insurance.

And we were not even feeling responsible for people’s care or outcomes. Studies suggest that those who were—nearly half of mental health professionals—experience burnout.<sup>11</sup> This group includes psychiatrists, over half of whom report burnout early in their careers.<sup>12</sup> Specific reasons for burnout may include lack of perceived job control, heavy caseloads, the mental health professional’s own mental health history (many are called to this line of work for a reason—personal or familial), and limited or poor supervisory support.<sup>13</sup>

The ways Americans respond to mental health emergencies can no doubt be traumatic, both for staff and the patients they serve. All these findings point to the strong need for more trauma-informed care in inpatient settings. Trauma-informed

care focuses on not *retraumatizing* patients with procedures that resemble aspects of past abuse or violence, such as using handcuffs or restraints, forced or threatened medications, involuntary commitment, boundary violations, or police “takedowns” or exposing people to other, extremely sick or frightening patients.<sup>14</sup>

These recommendations are important because many of the young people the research team engaged with had significant trauma histories and so were vulnerable to the possibility of being retraumatized. Previous chapters mention some of the connections between stress and psychosis, but to be clear: two-thirds of our participants had a significant traumatic experience that occurred at some point during their lives such as physical assault, sexual assault, or the death of a parent, and my research team was not asking explicitly about trauma in our interviews, because we were focused more on experiences of care and how that affected treatment decision making. These past events just came up. Many of the traumatic events they shared had happened in childhood. But given that the interview protocol and demographics sheets did not ask explicitly about trauma, we missed the opportunity to document systematically the potential traumatic impact of structural racism, inequality, colonialism, and war on the immigrants and persons from ethnoracially minoritized groups in the study.<sup>15</sup> Future research might delve more specifically into these areas.

The negative mental health impacts of traumatic life experiences make a person more likely to experience a psychiatric hospitalization, which is then often a retraumatizing experience. Research suggests that traumatic stress is at the root of many experiences and behaviors that lead to a psychiatric hospitalization for children and youths.<sup>16</sup> Among adults, 25 percent of men and 40 percent of women in inpatient psychiatric units had a history of interpersonal trauma.<sup>17</sup> In one study, nearly all of the adolescents in an inpatient psychiatric unit reported exposure to at least one traumatic event such as being a witness to or victim of community violence, witnessing family violence, or being the victim of physical or sexual abuse.<sup>18</sup> Evidence also points to a dose-response effect in which the severity of one’s clinical symptoms reflects the “dose” of trauma they have experienced.<sup>19</sup>

Not surprisingly, high levels of childhood adversity have also been associated with the presence and persistence of psychotic experiences.<sup>20</sup> Childhood trauma is common for people experiencing psychosis,<sup>21</sup> and individuals with a psychotic disorder are more likely than those without one to have experienced childhood trauma of all kinds (e.g., emotional, physical, sexual).<sup>22</sup> Individuals who experience childhood sexual abuse are more than twice as likely to develop psychosis as those who do not.<sup>23</sup> Moreover, recent evidence suggests that sexual assault or abuse at any point also makes a person more vulnerable to developing psychosis.<sup>24</sup> Lady Gaga’s revelation that she experienced psychosis in the aftermath of sexual assault when she was 19 years old is only one of many examples.<sup>25</sup>

The research literature and my data both make plain that young people with early psychosis are likely to have experienced significant trauma. Yet our current

forms of care fail to address this likelihood. People experiencing mental health issues have described how the emergency room environment can trigger fears or traumatic memories, which may stop them from seeking support.<sup>26</sup> Harsh lighting, strong smells, high noise levels, and a hectic environment can increase patients' stress, trigger feelings of panic, and have a negative effect on their well-being and ability to cope.<sup>27</sup> Emergency rooms lack private or quiet therapeutic spaces, making people less willing to disclose mental health issues.<sup>28</sup> All of these conditions could definitely be found at Shady Elms.

Moreover, in several studies that explored the experiences of people with mental health issues, patients described emergency department staff's communication with them as "pushy," disrespectful, insensitive, and judgmental.<sup>29</sup> Patients felt dismissed and stigmatized and were unsure whether emergency department staff understood their needs.<sup>30</sup> This may be especially relevant in nonpsychiatric emergency spaces where the focus is not on mental health treatment.

Although Shady Elms *was* dedicated to psychiatric emergencies, there were still traumatizing procedures. Demeaning physical examinations like the "squat and cough" routine that Miranda experienced can also cause unintentional harm to patients.<sup>31</sup> These perceptions can be exacerbated by staff threats of using force or the actual use of force, with patients describing being yelled at, held down, and restrained—all practices that I witnessed during my time there.<sup>32</sup> These staff behaviors and methods can increase the severity of patients' signs and symptoms, heighten their risk of suicide, and reduce their willingness to seek support in the future.<sup>33</sup> Long waiting times before visiting with a medical professional like a psychiatrist—also common at Shady Elms—also contributed to people's concerns about compromised care, exacerbating their hopelessness, disempowerment, anxiety, and fear of being held against their will.<sup>34</sup>

Nor do the problems stop at the emergency room. One rigorous study revealed high rates of reported lifetime trauma occurring in all psychiatric settings, with one-third of patients reporting physical assault, nearly one-tenth reporting sexual assault, and almost two-thirds witnessing traumatic events.<sup>35</sup> Over half were frightened by the dangers posed by other patients. Reported rates of institutional measures of last resort were also high: two-thirds had been handcuffed, more than half reported involuntary restraint, and nearly one-third reported experiencing a "takedown." From start to finish, the current emergency health care system takes an already traumatized and stressed population and subjects them to more trauma and stress. It also offers very little training, supervision, or support for the mental health professionals trying to help them, who themselves are exposed to trauma and suffer from burnout.

. . .

This chapter indicates some of the many ways that a psychiatric hospitalization can be traumatic: by stripping a person of their identity, their loved ones, and their

safe space; by denying them ways to orient in space and time; by making them feel disempowered through subjecting them to strong authority figures who allow them little power or say over what happens to them; by denying them collaborative conversations whereby they work together to plan the next steps of their treatment; by using restraints; by forcing people to take medications against their will—the list goes on.

These sources of possible trauma led me to wonder, Is there an evidence base for how to do trauma-informed work in psychiatric settings? Are there existing practices that can help people with traumatic histories have a less disorienting and traumatizing hospitalization experience? The answer is yes. From my review of the research, I found a lot of good information about what to do and not to do to reduce and address trauma in psychiatric settings. These best (and worst) practices are discussed in chapter 7, but now we turn our attention to what happened to the young persons during the critical period after discharge, when positive outcomes are typically thought to result from continuing treatment. It turns out that many young people do not follow up with any mental health provider. For the persons in our study, we observed how they made decisions about whether using mental health care was going to help them move toward the future they had envisioned for themselves or if they instead refused the care on offer. More important, we wanted to know why they decided one way or the other.