

Introduction

Under Pressure

So many people are touched by all this stuff, but for some reason or other they don't want to talk about it—in the workplace, in schools, everywhere. I firmly believe that if that comes out, there will be more acceptance, and people will be more prone to open up and say, "Okay, this is really how I feel, and we are in this whole thing together." Because it's a life-changing experience, and it's gonna change your lives obviously, but I would hope that it would be for the better.

—SANDRA (CORRINA'S MOM), AT HOME, WEEK 12

Corrina turned up the volume on her television to drown out the noise of the neighbors carrying on. The apartment walls must be thin, she thought, and her new neighbors always left their television blaring. It was like trying to relax in a hotel room where the person next door was watching the Super Bowl at full volume.

Hours later, longing for sleep, she shut off her TV, but the neighbors' TV droned on. She banged on the walls. No response. She knocked on their door. Nothing.

Corrina curled up on her couch, wishing it would all go away. She buried herself in the pillows. No change. She plugged her ears with her fingers. Still there. She tried her swimming ear plugs. The noises seemed louder.

What the hell?! she thought.

Then, Corinna realized she must have taken some LSD. Her new boyfriend, Colby, had introduced her to the psychedelic in the past few months. She had been stressed trying to take care of her mother, who had been unwell, while also taking a full slate of classes. LSD made her feel better. It made the unusual things happening to her seem more normal—everyone had weird experiences on acid. It felt good to be around other young people who had weird experiences and then get back to life as usual the next day, even if she sometimes did not get back to normal quite as quickly as the others.

She sighed, relieved. Her boyfriend, Colby, could help her with this awful trip, she decided, so she grabbed her car keys to drive to his apartment. However, once she got into her car, she remembered that Colby was out of town. It was summer. She was just there for summer school. So she sat there, in the ninety-plus-degree heat of a Texas summer night, trying to decide what to do. She cracked her driver's side window, but not too far. She did not want someone to grab her.

And then, as she sat there, she began to see all the dots connecting. It was so obvious—how had she not noticed before? Her life was a lie. Her name was not Corrina. She was really an angel named Karina. Her mother, Sandra, was not her mother but rather an evil impostor from “beyond the veil” sent to control her. Her stepfather, Adam, too. Sandra and Adam were fake. They were demons sent to oppress her powers.

Overwhelmed, Corrina banged the steering wheel and hollered. A building resident spotted her while they were trying to park their car. Afraid to approach her, they called the police. It was very dangerous for anyone to sit in a parked car with the engine off in the intense heat.

The police and EMTs responded quickly. Corrina gave them her driver's license when asked and tried to explain that she was an angel. They asked her to please step out of her car. Getting out of the car made sense. She opened the door, and an EMT took her arm and guided her toward the ambulance. They said she needed to be hydrated as soon as possible. She did feel awfully thirsty.

But then, she heard a policewoman spelling her name on the dispatch. C-o-r-r-i-n-a.

The police must be in on it, too! she thought, frantically. *They are saying the wrong name!*

She tried to run away.

The next thing she could remember was waking up and feeling terrified in the Shady Elms emergency room.¹ She had no idea where she was and had never been there before. She thought she might be dead or in between life and death. She knew the demons had put her there.

A few days later, the hospital released Corrina with a new diagnosis: psychosis not otherwise specified. She had not been on LSD; in fact, her substance screen was clear except for cannabis. Her mother, Sandra, picked her up. Sandra was given almost no discharge instructions by the hospital except to give her daughter the prescribed antipsychotic medications.

Between August and November, Corrina stayed with her mother and stepfather in a nice urban neighborhood with mature trees, emerald lawns, and the occasional water feature. Smaller children played in the front yards because pools took up the backyards. Neighbors said hello. But during this time, Corrina mostly stayed inside. She also stopped answering the phone and texting people who knew her as Corrina—they were all part of the evil conspiracy. Sometime in October, Corrina decided to explain everything on her Facebook page. She posted that her real

name was Karina, that she was an angel, and that Corrina's life was a lie. For those of her friends not on Facebook, Corrina added posts on Instagram and Twitter.

Then, she abruptly started leaving the house for hours at a time on foot. No one—neither her boyfriend Colby nor her parents (nor Corrina when asked later)—knew where she went. In fits of rage, she sometimes smashed, ripped up, or burned her parents' and her boyfriend's property, including precious, irreplaceable items such as photographs and memorabilia. After wrecking her parents' living room and then her boyfriend's apartment on two separate occasions, Sandra gave her a choice: "We can call the police to get you, or you can let me drop you back off at the hospital, but you need some help."

Corrina did not want to deal with the police again, so she agreed to return to Shady Elms. While she was in the hospital, Sandra went through her car looking for illegal drugs. When she opened the glove box, several unopened bottles of prescription antipsychotic medications fell to the floor. Corrina had not been taking her medication.

At this point, I met and interviewed Corrina for the first time when she enrolled in my study on treatment decision making for young people experiencing early psychosis. I had permission to recruit people from the emergency room for interviews during their inpatient stay, and I followed ethical guidelines to do so, which included a lot of rules.² The nurses told Corrina I was coming to meet with her, and so she was waiting to talk in a bright, glassed-in cube, designed so that everyone within a fifteen-foot radius could see but not hear us. She shivered in her thin hospital scrubs. I offered her my blazer, and she draped it over her shoulders. Her stringy, unwashed brown hair fell across her protruding collarbone.

Her hospital unit was loud—open and echoing with the sounds of the television, people talking and shouting, phones ringing—a sensory overload. Corrina startled at every bang and spike in noise. She barely spoke above a whisper. She seemed very worried about "the demons."

A few weeks after she got out of the hospital, I was invited by Corrina's mom to visit their home. My team always did follow-up home visits and interviews in pairs for safety, so a research assistant accompanied me. When we arrived, Corrina sat in a wood-paneled living room darkened with blackout curtains. Her eyes, she said, were sensitive to sunlight. She sat in an oversized, black leather chair. As my eyes adjusted, I noticed a scraggly old terrier snoring at her feet.

Corrina said she was feeling better. A week after she returned home from her last hospitalization, she had awakened from her nap knowing that she was Corrina, not Karina.

"Like Rip Van Winkle!" Sandra joked.

It had taken four months, five different antipsychotic medications, and a nap for her original personality to return. Everything was not magically fine, though. When I asked her how she was doing, Corrina picked at her nail polish.



FIGURE 1. Cartoonist Emily Flake's rendering of the situation faced by young persons seeking help for early psychosis. This image shows just how vulnerable young people are, the precarity of the help being offered, and the likelihood that care will "bounce" them into a place that may not be so helpful—and could possibly even be harmful. From Octavio N. Martinez and Neely Myers, "We Are Failing Young Adults with Psychosis," Hogg Blog, Hogg Foundation for Mental Health, October 19, 2016, <https://hogg.utexas.edu/we-are-failing-young-adults-with-psychosis>; illustration by Emily Flake.

“I’m really disappointed. I’m just mad about myself, because I don’t understand what to do, and I feel like I’ve really screwed up a lot of opportunities.”

She started to cry.

Corrina had lost months of her life to her mental confusion and had burned many bridges with her school, family, boyfriend, and friends. When Corrina graduated from high school and left home, she was the smart, pretty cheerleader who did lots of volunteer work and was on her way to a good college. Now, rather than being on her way to a happy, independent successful adulthood, she was back at home, with a terrifying diagnosis, little understanding of how she had reached this breaking point, and no clue how to get back on track. Her future, which once looked so bright, now looked disturbingly uncertain.

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The United States—along with much of the Western world—is experiencing what many experts are calling a youth mental health crisis. In 2019, the US surgeon general’s general advisory *Protecting Youth Mental Health* warned of a frightening upsurge in adolescent mental health needs—a new threat to America’s well-being.³ Indeed, over the past fifteen years, there has been a forty percent increase in the number of high school students who report feeling so sad and hopeless they could not participate in daily activities, with one in three claiming they felt this way.⁴ Nearly half of those high school students who felt hopeless also reported making a suicide plan—a 44 percent increase since 2009. Suicide rates for youths ages 10–24 rose nearly 60 percent between 2007 and 2018, making it the second leading cause of death for this age group.⁵ And in 2021, over a third of high school students reported experiencing poor mental health, with a disproportionate impact on Black and Latino youths.⁶

Of course, as we all know, the COVID-19 pandemic did not help. Emergency department usage and psychiatric hospitalizations for young people have risen, as has demand for psychiatric hospital beds.⁷ At the same time, over 150 million people—nearly half of the population—live in federally designated mental health professional shortage areas.⁸ The costs of this crisis and the lack of access to mental health supports are considerable. Untreated mental health symptoms can lead to poor performance at work and school, interpersonal violence, expensive hospitalizations, and death by suicide—the list goes on.

In addition, young adults are especially vulnerable to experiencing serious mental health concerns—often labeled biomedically as depression, bipolar disorders, and psychotic disorders—that have not yet been identified and so can go unaddressed. These nearly always begin in adolescence, before the age of 25.⁹ Psychosis symptoms—such as hearing voices others cannot hear, which can occur across a wide range of diagnoses—often crest at a point known in the clinical literature as a *psychotic break*. For many, psychosis symptoms are episodic and begin as waves,

some stronger than others, that eventually become overwhelming—a time I think of as a *breaking point*.

Corrina hit a breaking point and had a psychotic break in her apartment when she heard a television blaring that did not exist and thought that demons posing as loved ones surrounded her. A psychotic break is a complete break with reality, which may include hearing voices, having visions, or fervently upholding ideas that others have trouble accepting as real.¹⁰ These disorienting symptoms of psychosis often begin during a person's early 20s, when they are under tremendous pressure to become a valued, independent American adult. In the United States an estimated 100,000 people experience a first episode of psychosis every year.¹¹

Research suggests that there is a “critical period”—a three- or four-month window—after an initial psychotic break when engaging a person in specialty early psychosis care is essential for preventing negative long-term outcomes.¹² This period was the target of this study. Others argue that there is period of up to five years after initial onset when early intervention can help, which is today the target of most early intervention for psychosis programs around the globe. Even so, as of 2022, there were only 381 programs offering specialty early psychosis care in the United States called *coordinated specialty care* (CSC), which was estimated to leave about 75 percent of persons, or more than 75,000 young people, with new cases of early psychosis per year without specialized services in the United States alone.¹³ In addition, between 20 and 40 percent of the young adults ages 18 to 35 in the United States who have access to that specialty early psychosis care refuse further treatment.¹⁴

The study that informs this book used an anthropological approach to understand why young persons who were experiencing a psychotic break were refusing care so frequently during that critical period. Anthropologists have long been interested in the ways people's illness experiences are identified, understood, labeled, and treated in a variety of social contexts, and how people adapt to those experiences. Core anthropological studies of serious emotional distress, for example, include writings on schizophrenia, bipolar disorder, autism, depression, and addiction.¹⁵ Other works focus on adolescents who have been identified as needing mental health care more broadly and the kinds of care offered to them.¹⁶ In addition, the contours, ethics, and variations of Western biomedical approaches to perceived psychopathology as they have been taken up in a variety of social contexts have been well researched.¹⁷ Several notable collections cross over many of these topics in psychological and medical anthropology.¹⁸ These works have collectively taken up questions around psychiatry and mental health in terms of care, ethics, cultural relevance and humility, the social life and power of diagnostic labels and medications, the social and structural determinants of health, and the impacts of both biomedical and local forms of care on the people who use them.

Joining in this scholarly conversation, this book is based on three years of ethnographic research with young persons from culturally diverse backgrounds

and their key supporters, research that followed many of them—like Corrina—from their initial hospitalization for a psychotic break back into their homes. My goal was to understand why young people chose to use or to refuse mental health care after a crisis. Effectively helping young people in crisis and, ideally, preventing one before it happens are some of the greatest mental health challenges of our time. This book will address these challenges from a fresh perspective by starting with the everyday experiences of young people and their families during the critical period following their initial hospitalizations. After all, what greater experts are there than those who have been there?

I know firsthand—from experiences in my own family—that psychosis disrupts lives and breaks hearts. Inspired by my family's struggles, for the past twenty years I have been researching how we—as a society, as mental health care workers, and as individuals—can better support people who experience psychosis. What I have learned through my work is that healing from a psychotic break has material, medical, and moral dimensions that require equal attention to promote mental health.

The material dimensions include the spaces and places where people are made to seek mental health support and the resources offered to them, so often shaped by the structural and social determinants of mental health. These determinants include, among other factors, structural racism, lack of employment opportunities with adequate mental health insurance, access to mental health providers, vocational and educational supports, transportation, and housing. All these factors shape a young person's ability to access and use care.

In referring to the medical dimension, I mean the nuts and bolts of care as construed by Western biomedicine and constructed by public health initiatives, which (when done well) can be important resources for people experiencing a mental health crisis and their families. These may include therapeutic supports such as well-informed prescribers, trauma-informed psychotherapists, a place of respite during a crisis, family support specialists, substance abuse counseling, peer specialists, in-home visits, family therapy and education, and alternative health options. At the current moment, many of these basic structures are not available to young persons experiencing early psychosis, a fact that becomes clearer as the book unfolds.

I also highlight the moral dimension, the greatest novel contribution of this book, by pointing to what feminist philosopher Margaret Urban Walker identified as the intimate “moral understandings” developed and shared between people who care about one another, understandings that then reflect their expectations of and responsibilities to one another.¹⁹ Usually such moral understandings are based on shared cultural notions of what is good, beautiful, and true for one's social group at any given moment. These moral understandings, I argue throughout, are seriously compromised by the symptoms of psychosis and then exacerbated by our societal response to them. By using the term *moral*, I am also drawing on an

anthropological approach to morality and health that seeks to identify and understand what is life affirming in a specific social context for a specific person, based on the desires and goals they share with the people they care about, and how that process is also key for mental health.²⁰

Meeting the expectations of shared moral understandings about what it means to be a “good enough” American adult is crucial for adolescents coming of age in American culture. It is also often the very thing that is compromised between young people and their loved ones during a mental health crisis.²¹ Moral understandings need to be repaired when damaged—or, more ideally, protected in the first place. Otherwise, as I demonstrate throughout the book in so many ways, a young person will struggle to have enough moral agency to move forward as an independent adult.

Building on the work of other anthropologists, sociologists, and moral philosophers, I thus define moral agency, the theoretical foundation of my work, as having the wherewithal to aspire, and the intentions and necessary resources to achieve, what one understands to be a good life. Having moral agency means that one person and another have a shared sense that both can uphold their shared moral understandings and so be good enough (if not excellent) to each other, and therefore worthy of an intimate relationship. Being understood as a person capable of being good to another person—in whatever current social context—is essential for the person, their desired relationships, and their vision of a good life to flourish.²² Having enough moral agency to be seen as a “good enough” person makes possible enriching social connections with desired others, such as romantic partners, friends, family, elders, community groups, and employers.²³ Having relationships with people who see you as a moral agent, allow you to have a relationship with them, and also give you space to try and sometimes fail to be a good person creates opportunities for young people to take meaningful action and move forward in life, at least in the United States.²⁴

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I have been developing my conceptualization of moral agency since 2010.²⁵ The importance of moral agency for mental health first emerged as a relevant construct after three years of research in a recovery model-based psychosocial rehabilitation agency, Horizons, that failed to help its clients recover in any meaningful way, which was the topic of my first book.²⁶ The agency’s prescribed “journey of recovery” to social belonging and valued citizenship for its “members,” as it called individuals with psychiatric disabilities, was based on long-held American moral values about what makes a person good—namely, the ability to independently demonstrate one’s rationality, autonomy, and ability to work hard. This set a high bar for the mostly unhoused people with serious psychiatric disabilities whom I engaged. They aspired to lead a good life as others expected but had few resources or relationships with which to get started. Their daily life was fraught in ways that

were only exacerbated by a seemingly well intentioned recovery-based mental health policy and practice that ignored the very real structural and relational limitations of their everyday lives.

In 2011, I led another study that asked how primarily African American users of a peer-run public mental health clinic in New York City attempted to “take charge” of their own lives. I found that many of the service users there had long histories of institutional marginalization in “learning disabled” classrooms, foster care, juvenile detention, substance abuse facilities, jails, and mental health service settings.²⁷ Many had little opportunity to share their life stories in ways that others valued. This work helped me identify what I call *autobiographical power*, or the ability to be at least the editor of your own life story, as essential for a person’s sense of moral agency.

Based on this work, I wrote several pieces unpacking further the concept of moral agency, which I could see operating in the stories of people seeking mental health recovery. I elaborated on moral agency as both the intention and means to aspire to a good life that make possible intimate relationships with others. I described how persons who experience a mental health crisis often have a breach in their life narrative, or an Aristotelian *peripeteia*, that erodes their sense of connection to others. After this breach occurs, everyone involved works toward reestablishing that connection by cultivating the person’s moral agency, which has three components: autobiographical power, the social bases of self-respect, and peopled opportunities to try and fail.²⁸ Again, autobiographical power is the ability to at least be the editor of one’s own life story in everyday conversations with others.²⁹ John Rawls’s notion of “the social bases of self-respect” highlights the importance of meeting locally valued ideas about what it means to be respected so that you can also respect yourself as a person who belongs.³⁰ “Peopled opportunities” are social circumstances that enable one to have the opportunity to try (and also sometimes fail) to be recognized as a good, accountable person by others via shared moral understandings that make intimate relationships possible.³¹

Following up on this research, in 2014 a new, National Institute of Mental Health (NIMH)–funded research team that I assembled at Southern Methodist University in Dallas, Texas, began the study that informs this book.³² This time, my focus was on what guided young persons from primarily ethnoracially minoritized groups’ decisions about treatment after an initial emergency hospitalization for a suspected psychotic disorder.³³ The goal was to understand what mattered most to young people ages 18 to 34, and their self-identified key supporters, during the aforementioned critical period—the first few months after an initial hospitalization when engaging in mental health care makes a difference for longer-term outcomes.³⁴ NIMH researchers work in teams, and I designed this research in partnership with my consultants, who included Michael Compton, a psychiatrist with expertise in African American pathways to care and what contributes to treatment delays for psychosis; psychiatrist and early intervention expert Lisa

Dixon; and the seasoned mental health services researcher and ethnographer Sue Estroff. In addition, as with all NIMH grants, the program officer, Susan Azrin, secured important expertise and feedback from anonymous reviewers on how to best refine my methods and approach. When we received additional funding from the Hogg Foundation for Mental Health Research in 2015, I also added two additional consultants: peer provider and director of the Hope Center, Maggie Caballero, and community psychologist, mental health services researcher, and young person with lived experience Nev Jones.

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Early-intervention research suggests that if young people and their families engage with high-quality, evidence-based mental health supports early enough, they avoid negative long-term outcomes such as homelessness, repeated hospitalizations, and suicide. In this model, psychosis is thought of as similar to cancer: there are “stages” that progress from the earliest phase of social oddities and psychotic-like experiences to a “first break,” or complete break with reality.³⁵ The idea is to catch the illness before it spreads—but, with psychosis, not into the rest of one’s body but into the rest of one’s life.

Well-designed, compassionate early-intervention programs for young people who have experienced a psychotic break are now typically called coordinated specialty care in the United States and are thought to be cost-effective and prevent longer-term social problems for young people experiencing a mental health crisis.³⁶ Even so, one recently published (and controversial) paper has suggested the best outcomes may be limited to persons with greater socioeconomic resources,³⁷ and another has argued that users did not experience long-term, gainful employment as a result of these programs.³⁸ In addition, research shows that even when these specialty services are on offer, for every ten young adults who experience a psychotic break, up to four or five refuse further mental health care after their initial hospitalization for psychosis, thus putting them at risk for further episodes and worsening outcomes.³⁹ It may be even more difficult to engage young people with early psychosis from ethnoracially minoritized groups, which have long struggled with systemic and institutional racism, distrust of medical care, and high levels of stigma against people deemed mentally ill.⁴⁰

To explore how to make mental health services for psychosis more appealing to youths experiencing a mental health crisis from a range of cultural backgrounds, my research team engaged with 47 young people—about half of whom self-identified as women and half of whom self-identified as men—ranging in age from 18 to 34. About half also self-identified as Latina/o,⁴¹ one-third as Black,⁴² seven white, four South Asian, and one Middle Eastern. In addition, about half were first- or second-generation immigrants—the former meaning they were born outside the United States and the latter meaning one or both of their parents were.⁴³ We also talked to 19 of the young people’s self-identified key supporters—typically

a woman and parent, namely their moms. We also interviewed providers of mental health care for Black and Latina/o youths and Black pastors with primarily Black congregants to learn more about the needs and challenges of accessing care for persons from minoritized groups.

This is not to say that the study had a representative sample or that this book offers a definitive account of any of these groups, but I can say with confidence that this book is inclusive and does not focus on white youths. There is a moral imperative to better serve individuals who have been disproportionately impacted by racist policies in the United States (e.g., redlining, overpolicing, the US “war on drugs”), and this book contributes to the literature that responds to this imperative by sharing some of these individuals’ experiences when dealing with a mental health crisis. A sample that represents the interests of young persons from a range of cultural backgrounds is important because any broader mental health care reforms must meet the needs of an incredibly diverse nation. It is also important because persons from minoritized groups in the United States experience a higher risk and incidence of symptoms of psychosis and psychotic disorder, and also have more difficulty finding and accessing appropriate services.⁴⁴

The presence of first- and second-generation immigrants in this book is also relevant in that “seeming different” increases one’s risk of developing psychosis.⁴⁵ A robust literature on immigrants in Europe suggests that immigration increases psychosis risk. In Europe, first-generation migrants face an increased risk of developing mood disorders, and migrants and their children are at an even higher risk for developing psychotic disorders.⁴⁶ These phenomena seem associated with social exclusion and minoritized status.⁴⁷ Migrating from outside Europe, having Black skin, and being from a socioeconomically “developing” country had the highest impact on psychosis risk.⁴⁸ In the United States, the amount of research on immigration and psychosis is limited, but social context clearly shapes the development and experience of psychosis, just as it shapes the development and experience of becoming a valued adult.

Other research finds that Black and Latino individuals are overrepresented in the population of patients diagnosed with psychotic disorders.⁴⁹ One study showed that Black children were almost twice as likely to experience schizophrenia, though the higher incidence in this population may have to do with misdiagnosis or socioeconomic disadvantage, and further research is needed.⁵⁰ Psychologist Deidre Anglin argues that there may also be a compounding effect of social and environmental stressors related to structural racism and inequality for Black and Hispanic or Latino US populations, such as obstetric complications, police oversurveillance, neighborhood violence, collective trauma, and adverse childhood events, all of which make people more prone to developing psychosis.⁵¹

Adverse childhood events at the individual, familial, or neighborhood level also increase psychosis risk and can include childhood maltreatment, exposure to violence, the loss or incarceration of a parent, parental unemployment, having a

darker skin in a lighter-skinned neighborhood (or vice versa), and perceived discrimination.⁵² Many young people in my study talked about these kinds of events. The experience of increased risk of psychosis for sexually minoritized individuals and people with hearing impairments may also be explained by social and environmental stressors related to discrimination and social exclusion.⁵³

To the extent possible, we recruited persons from minoritized groups for the study. I and core members of the team—primarily Anubha Sood (a NIMH-funded postdoctoral fellow) and Katherine Fox (an SMU PhD student in cultural anthropology) and eventually, with additional funding from the Hogg Foundation for Mental Health Research, Nia Parson (an associate professor of anthropology at SMU with fluency in Spanish)—recruited nearly all of the young adults enrolled at Shady Elms with the generous support of the hospital leadership, its staff, and its internal review board (IRB). Shady Elms was a psychiatric emergency-only hospital that, according to institutional data from 2014, served 23,000 people in crisis from seven counties in North Texas each year. The hospital reported having about two new first-episode psychosis patients per week. My team recruited and gained consent from those young people, such as Corrina, while they were in the hospital. We then followed up with them after their release in community-based settings to engage them in further interviews and ethnographic home visits over the next several months as they struggled to, as they often put it, “get back to normal.”

Anthropologists often use ethnography to understand what everyday life may be like for our interlocutors. What sets ethnography apart from other research methods is its slow accumulation: anthropologists spend a lot of time with the people we are trying to understand, and these engagements occur over a relatively long period. Rather than coming in and administering a survey or questionnaire in a “one and done” approach, an ethnographer may engage someone in an interview or offer a survey, but then will return repeatedly to confirm and refine their observations and interpretations with the help of their interlocutors. Ethnographers are looking not for what someone said once but rather for *iterative* patterns, or repetitions, in what that person and others say over time.

Another hallmark of ethnography is that researchers reflect on the way their own position, or positionality, affects their relationship with the people they are researching. In my case, I asked myself how my role as a white college professor at an expensive local university might affect the ways young persons and their families—with varying levels of education and income and a range of minoritized statuses—interacted with me. How might my presence and the power dynamics between us shape their participation and answers? And how might my own interests and desires—for example, as a family member of someone who experiences psychosis—shape the ways I ask questions or how I understand and interpret what my interlocutors say?

What I love about ethnography is that it allows me to establish a relationship with the people I am trying to understand. I get to know them. They get to know me. In this study, I regularly reminded the people whom I engaged: “Hey, you are the expert on this experience, and it is *your* experience, so *you* tell me. I do not know what it feels like to be a young person with early psychosis or their parent, but you do, and if you are willing to share, then maybe this research can help other people have a better experience by sharing your story.” And I meant it. This helped ease the power differential between us.

The members of my research team also brought their own positionalities to the table. I intentionally sought out lab team members who were under 35 (the cut-off age for the study) and who self-identified as persons with lived experience of mental health concerns or as persons from a minoritized group, or both, so that they could bring their lived-experience expertise into the conversations about the data collection and interpretation. Not all the team members met any of these criteria, but I did try.

Early on, the consultants and team members who self-identified as persons from minoritized groups, as well as the staff at the hospital, let me know that the young adults we were trying to recruit were most likely to trust and engage someone who looked like them. Over time, we added several undergraduates to my team, including young persons who identified as being from a minoritized group, both because the young persons seemed to relax around their peers and because the undergraduates could help the rest of us understand youth culture. We also brought on bilingual Spanish-language speakers to translate research documents, conduct interviews with those more comfortable speaking in Spanish, and transcribe the interviews into English. The conversations I had with my team were invaluable in critiquing and shaping the research approach, our follow-up questions and visits, and the way I have thought through the data we collected.

So it is through ethnography, as well as all the various perspectives and experiences that my research team brought to the effort, that we built relationships with the young people and their key supporters over multiple visits, initially at the hospital and then in their home or at a place in the community, such as a Starbucks Coffee shop, where they felt safe and comfortable, over the course of up to one year. These visits helped my team understand the young persons’ experiences over time in their own social context. We were thus able to take our time to explore their hopes, desires, fears, needs, and goals in a place that was comfortable for them, and they had time to trust us enough to share.

This proximity took a toll on the team. It is heartbreaking to see people struggling. Per the ethical research parameters of my project, we were limited to no more than four visits so as not to influence their treatment decisions. We were also supposed to cease following up with them after six months unless they called us first. We thus do not know what happened to those we interviewed over the

long run. Therefore, this is not a book of happy endings or finished stories, but of unfolding lives and the ideas they inspired.

One of the most important ideas that emerged from these data, from my perspective, was that paying attention to local forms of moral agency can shed light on what drives young people's decisions about medical treatment, and on how the treatment on offer both helps and hinders American youths in returning to a meaningful life after experiencing a mental health crisis. As I pondered the significance of these data and wrote this book, I came to understand that while many people see psychosis as a breaking point, a rupture from reality and in one's life plan, it could also be a turning point if we offered people the right supports. The good news is that there is a lot we humans can do, and this book points us to a better understanding of how we can help. It is about the United States, but I think it applies to many places—any place where young people are struggling. And, right now, that is everywhere.

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Typically, prior to their initial hospitalizations, the young people in my study were working toward a successful transition to adulthood. In the United States, there is no prescribed, structured, guided rite of passage to adulthood to help an adolescent make that transition. Young people must do it on their own. Thus, the young people I met were socializing and studying and trying to earn a viable income. They needed to establish their moral agency so that they had social credibility as independent adults. Again, moral agency is a person's ability to be seen by intimate others as a "good enough" person in the social context that matters to them, which makes possible the relationships they need to thrive in a culture where everyone is expected to be "self-made."

For young Americans, being healthy enough, attractive enough, and successful enough to secure intimate relationships with others constitutes three common cultural signals of having enough moral agency to thrive. My undergraduate students typically list these three items first when I ask them what it means to be happy. There are other ways to attain moral agency in the United States—participating in community service, belonging to a religious community, caregiving for relatives, becoming an Eagle Scout, serving in the military, rescuing animals, and so forth—but many young people equate an individual's good health, attractive appearance, and success at school or work with being good. American youths must be able to both work hard and play hard and seem healthy, attractive, and successful while doing so. This is the topic of chapter 1.

Some youths achieve these cultural signals of moral agency in high school. They may have been on an athletic team or were part of the band or a cheerleader like Corrina. Perhaps they were popular with peers, engaged in community service, and had good grades. These accomplishments signaled that they were a good-enough person to hire or have as a roommate or a romantic partner—all things

most Americans desire as adults. However, when youths leave high school, they are under pressure to prove themselves as moral agents all over again, but this time independently and often in a new place with unfamiliar faces.

A person with enough moral agency to be deemed a responsible, independent adult must have three key capabilities. First, they must have the intention and capacity to exercise autobiographical power, which is the ability to be the writer, or at least the editor, of their own life story. Second, they must be able to seek and secure the social bases of self-respect, and so be recognized by meaningful others as the kind of person they imagine themselves to be. Who we become is relational—it must be mutually agreed upon with the others we want to have in our lives. We must be good enough for the people we want to love us to accept us so we can belong. We first need to affirm that the role we have chosen as the editors of our own lives—be it pop star, stay-at-home mom, or astrophysicist—is the right one for us and that others respect us in that role. I cannot just walk around saying I am an aspiring hip-hop star or news anchor if no one else agrees that it's even a possibility. The third key capability for any person is to successfully negotiate peopled opportunities by practicing one's desired social role with intimate others who are willing to let one try and fail and try again.⁵⁴ It is quite likely that someone, especially as they are transitioning to adulthood, won't get it right the first time. So their loved ones have to be patient and give them multiple chances.

It helps to think of this phase in the terms of theater: "All the world's a stage," to borrow from Shakespeare.⁵⁵ American youths are expected to fashion their own social role, convince others that they deserve that role, and then seek out opportunities to practice that role with audiences who then decide whether or not they are good at it and so can be respected in that role. Having the ability to do this—to craft oneself into a valued adult in American culture—requires moral agency.

These key components of moral agency—autobiographical power, the social bases of self-respect, and peopled opportunities—are not a given in the United States. They must be earned. It's actually very hard to do, and no one gets a manual or a guidebook. Young people starting the transition to adulthood will have earned some of these components in their home communities as they built up a tentative sense of moral agency before they turned 18 or graduated from high school. But at this point Americans ask their youths to go out and become self-made by finding their own niche—who they want to be—and then making a place for themselves in that niche.⁵⁶ We require them to start over in proving themselves to be moral agents, by themselves and to a new audience, by working hard and playing hard.

The American Dream is that anyone can become successful if they try hard enough. But America is not the meritocracy many imagine it to be. Some people get more chances than others. Imagine two young people in their mid-20s—Emily and Andre. Emily is white. Her parents are not rich, but they are comfortably middle-class. Emily is careful to craft a public persona that looks good in the virtual and real worlds. She projects the image of success. She is fit and well dressed. She

has a college degree from a reputable university and a nice job at a good company with a solid paycheck. She has her own car, apartment, and a loving girlfriend. Her dog has his own popular Instagram account. Emily “has it all.” If she continues to maintain her positive social status in the circles and communities that matter to her, she can tell her own story in her own way. Her loved ones will accept her story as true and respect her for it.

Emily has also been given opportunities to try and fail. And fail she has. When Emily was 18, she was arrested for trying to sell cannabis in a rock concert parking lot to an undercover cop. She was trying to cover the cost of her ticket and hotel room. Emily was convicted but did not go to jail, and her future employers did not hold that against her. People make mistakes, they said. She was young and had no other police record, so why penalize her for it? She spoke her truth, convinced her audience, had chances to try and fail, and became a valued American adult with access to the intimate relationships she needed to thrive. Emily had enough moral agency to live the life she wanted as a socially valued, good-enough adult.

Andre, on the other hand, is Black, and history, research, and common sense indicate that this makes moral agency more difficult for him to access in the majority-white culture of the United States.⁵⁷ Due to a long history of social, political, and economic disenfranchisement of Black persons in the United States, his family also has less material wealth to support him than Emily’s family. He has struggled since childhood with dyslexia, which went undiagnosed, and so he did not receive the additional educational supports he needed to thrive in school. He wanted to go to college, but his grades were not strong enough for a scholarship, and he could not afford it. With mostly low-income job opportunities available to him, Andre decided to focus on a music career. For a little while, being a musician attracted some women, but no one special to Andre. The band was not making a lot of money, studio time was expensive, and his mom wanted him to get his own apartment, so Andre decided to sell cannabis on the side. Like Emily, Andre was arrested by undercover police, but unlike Emily, he spent three months in jail. Unable to pay rent, he was evicted from his apartment. Upon his release, people were less willing to offer him employment when he reported his record. It was harder to get an apartment after an eviction. His bandmates seemed reluctant to reconnect with him. He became increasingly depressed and anxious.

Andre’s chances for making a successful transition to becoming a valued American adult were diminishing. He was losing his ability to become the kind of person he wanted to be. He wasn’t telling the story he wanted to tell and was rejected for the roles he tried to take on. He had few opportunities for a second try and was penalized for his failures. Andre did not have enough moral agency to nourish the relationships he needed to live life on his own terms. It was difficult for him to build up moral agency when others were reluctant to give him a chance to try.

All young adults in the United States are trying to become moral agents independently so that they can become people “good enough” to have meaningful lives

and relationships. However, the research suggests that many persons from marginalized or minoritized groups of all ages lack moral agency in contexts of transition when they are tasked with proving their moral value all over again with new sets of intimate others.⁵⁸ They must work extra hard to reestablish that they are a “good person” in order to access intimate relationships as they begin everyday life anew.

As feminist philosopher Margaret Urban Walker wrote:

Not everyone is allowed or enabled to tell just any life (or other) story. The stuff of lives to be told, the discursive means available for telling them, and the credibility of storytellers are apt to differ along familiar lines of class, gender, and race, perhaps along other lines, even rather local ones as well. Life stories, including moral histories, will take shape in response to specific constraints, and for some people may be shaped as much for them as by them depending on their “socially recognized credibility.”⁵⁹

. . .

Establishing moral agency is difficult for any young person. Add to this the disadvantage of being a person of a minoritized status and the experience of a mental breakdown, and the task of establishing moral agency can become extremely challenging. In fact, some of the very means that our culture offers to enhance moral agency are particularly dangerous to those who need it the most.

For example, many of the young people my team interviewed were encouraged by American culture to both work hard and play hard, and so they worked hard but also engaged in substance use. For young people in our study, substance use—and misuse—often led to entanglements with authorities. This led to losing moral agency with other adults—landlords, teachers, parents—and sometimes friends. It also contributed to treatment delays as families and young persons confused psychotic symptoms with substance misuse.⁶⁰ As with Corrina, who used cannabis and LSD to relax and fit in, young people in our study struggled to meet the expectation that they could play hard while also struggling with the onset of highly disorienting psychotic symptoms. This is the topic of chapter 1, “Work Hard, Play Hard.”

Nearly all the young people in our study also began to craft personal myths as explanations for their symptoms, narratives that typically made sense to the young people in crisis but not to others. For others, it signaled a break with reality—a phenomenon I unpack in chapter 2, “Into the Mythos.” It is hard to accept someone as an angel or Jesus or a superhero. When a young person tried to claim these identities, others questioned their ability to become a responsible and independent adult. Their moral agency was starting to break down, but the young person could not yet see it.

For most of the youths in our study, there was often a catalytic event—a person had to become dangerous to themselves or others (but not violent per se, as I explain)—before someone decided to call for help. In chapter 3, “Dangerous,”

I explore this phenomenon further. Once a family reached out for help, the people who typically responded to emergencies—especially mental health emergencies—were the police. For persons from ethnoracially minoritized groups, interactions with the police can cause psychological distress.⁶¹ Even so, most of the young adults my team interviewed came to the hospital by police escort because Texas law (and the law of many other states) requires that, to be hospitalized involuntarily, a person who is over 18 who is not under a legal guardianship must be admitted into the hospital from the custody of a “peace officer,” or someone who works in law enforcement.⁶²

Here again, the US mental health system is failing our youths. Being in police custody and then hospitalized involuntarily, I argue, led to the further loss of autobiographical power and the social bases of self-respect for the young persons in my study. It altered how they thought of themselves and how their loved ones thought of them. Even the handful of my study participants who initially went to the hospital voluntarily described how it affected their ability to be perceived as a good person later.

At most mental health emergency facilities, as discussed in chapter 4, “Disorientations,” the first few days after intake focused on controlling the person’s risk to self and others with sedation and restraints, assigning a diagnosis for medical insurance billing purposes, and deciding where a young person should go next—often determined by their insurance status, it seemed. The youths in my study were then often released with little continuity of care, no clear directions for next steps, and little to no family, educational, vocational, therapeutic, peer, or substance use supports. This means that peopled opportunities were often thin: most intimate others were now seriously questioning the young person’s credibility as the moral understandings between them and their loved ones broke down.

Families had little support in processing with others what had happened or in navigating what followed. For those limited to public insurance, the extended hospitalizations seemingly required by Medicaid or Medicare rules resulted in lost opportunities at work and school as employers, friends, and teachers had ample time to notice that something was terribly wrong. This typical response to psychosis, by both the medical community and the community at large, again diminished our interlocutors’ moral agency, thereby complicating their ability to continue their efforts to become valued adults. This also diminished their interest in continuing mental health treatment.

It does not have to be this way.

Far from being passive victims of a failed mental health system who could not think for themselves, the young people in our study, as this book illustrates, worked diligently to restore the moral agency they were losing even as they were losing it. They sought connection and recognition as a “good” person even in their most vulnerable and disorienting moments. More than half refused care, but it was not an irrational decision. Their decisions about whether to use or refuse mental

health care were grounded in their ideas about whether using that care was going to help them restore their moral agency and “get back to normal.”

In many cases when young people refused services, for example, their family did not support the idea of pursuing care. Some families wanted to rely on religious supports for healing. Others had such a strong bias against people who were “crazy” that their children moved away from the label as much as possible by rejecting care. Young people needed the moral and material support of their families to move forward, and many worked hard to not lose that support even if it meant refusing medical treatment. This book shares their stories.

On the other hand, half of the young people that completed the study did accept services: these were the service users. Often, they did so because their families encouraged or required them to do so in order to receive material and moral support. I share their stories, too. Chapter 5, “Users and Refusers,” focuses on young persons’ decision-making processes about using or refusing mental health care during the critical period. I also explore, in chapter 6, “Homecoming,” the struggles of families to support their loved ones and one another and move forward.

While Americans debate effective ways to reduce costly social problems associated with unaddressed mental illness, such as homelessness, violence, substance abuse, fatal police shootings, and rising suicide rates, the number of young adults reporting increasing amounts of serious emotional distress is rising.⁶³ There are services (though not yet widely enough available) that can help young people have better outcomes. But, no matter how widely available those services are, no one can force young people to use them outside a crisis situation.

The experience of psychosis does not happen in a cultural vacuum. Attention to American culture and how it complicates the transition to adulthood for all youths, and even more so for young adults experiencing symptoms of psychosis, is at the heart of this book. The mental health system in the United States is failing young people in crisis, and we must consider what can be done to address this crisis in terms of moral agency. Understanding how young people decide when to use or refuse services and the relationship between those choices and moral agency in the context of making a transition to valued adulthood is crucial.

Many young people experience symptoms of psychosis, but with stronger material, medical, and moral supports, they can move forward. Having a psychotic break need not permanently rob a young person of their moral agency; it can be a turning point toward a positive outcome instead. While focusing on the stories and decisions of young people and their families, I argue that attending to young people’s moral agency during this period of incredible vulnerability and potential is at least as important as medical treatment, because young people will not seek out supports that they perceive to be—or that are—misaligned with their moral lives and therefore socially harmful for them.

Throughout the book I indicate multiple breaking points when things could be done differently to prevent or alleviate the crisis. In chapter 7, “Turning Points,”

I present what we can do to change things for the better. Mental health care can protect and replenish moral agency and so better engage young people in much-needed early material, medical, and moral support. This book shows all of us how, whether we are persons experiencing psychosis, intimate others, health care workers, advocates, policy makers, or academics. Together, we can work toward constructing a pathway *through* care for young persons with early psychosis—one that doesn't just bring them to the hospital emergency room but guides their families and them through the care process and back into everyday life.⁶⁴ First, however, we as a society need to develop a radically compassionate understanding of the challenges young people and their families face when they encounter the breaking point of psychosis so that we can instead transform this moment of crisis into a turning point for the better—a moment when the right supports are provided to a young person who needs that extra support to become a moral agent living out their full potential.