

Turning Points

You don't know what to expect, and you don't know how to get to the next point. So, it is—it's very murky. After overcoming that, people need something good to look forward to and work towards. Otherwise, you could just get really depressed and go play in traffic. You know?

—AMY, AT STARBUCKS, WEEK 12

I mean, the future—I don't know—kind of scares me because you don't understand if you never had schizophrenia. Like it just—I know I'm probably going to have to do something, but it's just like—it's like what can you do? I don't think I can be productive, like, I don't know. I don't know.

—MICHAEL, AT HOME, WEEK 20

Advice for others? Hmm . . . Maybe if you guys wanted to explain to people this isn't something to be ashamed of and this isn't something that can be prevented even, so you have to work through this and realize that this is where you're at and there's nothing you can do about it except enjoy it and make the best out of it.

—CORRINA, AT HOME, WEEK 6

A young person in the United States learns how to be a “good enough” person based on shared moral understandings about what is good, beautiful, and true in their local moral worlds, which are shaped by their everyday mutual relationships with the people they care about and who care about them, such as family, close friends, and mentors. To become a respected adult, they must then go out into the world and prove they are moral agents capable of developing new shared moral understandings with a new community of their choice. As they seek to become a moral agent in social worlds beyond their families, they must learn how to belong in new ways.

Young Americans are expected to leave home and choose with whom they want to belong next—coworkers, classmates, people training for the same craft or

military branch, people who share a hobby or religious affiliation, who are in the same fraternity or sorority, or who enjoy volunteering or playing an instrument or sport. Sometimes, their first attempt at fitting in leads them to join a community of people that may not be conducive to longer-term success. Sometimes, young people make choices that push back against religious or other cherished moral understandings held by their family or home communities, and their parents do not approve.

Regardless, young people typically are expected to develop their own “tribe,” if you will, that recognizes them as a good person, is willing to give them a chance, and that respects them for who they are as they move into adulthood.¹ In this way, young people thrive in a culture that expects them to become independent, because regardless of how independent we are, everyone needs other people to get by. While there are exceptions, most are not supposed to get this kind of moral agency from their family: they are expected to break away from their families and prove their ability to achieve independence even if they come back home eventually. If they do so successfully, and with a group of other relatively successful people, they might be set up well to become a valued adult. This is one of the main functions of American college life: to connect young people trying to become independent with a new set of people for fun and to work toward success together as moral agents—people who together can move forward with positive stories and mutual self-respect through the opportunities and connections they can offer one another along the way.

For some young adults, as we have seen, this step can go disastrously wrong. A psychotic break is a serious setback for a young person’s attempts to prove themselves as a good person with anyone. New friends, old friends, and family members will wonder if they still share or are able to share with the young person core moral understandings about what it means to be a responsible and trusted friend, family member, or adult—an understanding that binds people together.² The young person feels this doubt, too. As the previous chapters show, their mental breakdown is also a moral breakdown that at least initially compromises their relationship with others and even their own self. It depletes their moral agency.

When they start to feel better, the young person has trouble understanding why, when they were psychotic, they chose to harm relationships and jeopardize opportunities that mattered to them so deeply. They question their own self and motivations: Am I a good person? Who was I and who am I going to become? Can I trust myself?

As Michael tried to explain, “Imagine you just being normal one day, and then it’s like somebody taking control of your mind, and it’s like your mind is holding yourself hostage. Like anything could happen at that point. Your mind could tell you to go shoot up a building and you would think it’s because you’re doing it for a just cause.” Of course, this did not apply to him: his delusions were even worse, he thought, because they led him to try to harm his own niece. Psychosis can be

extraordinarily frightening. It can make a person dangerous to themselves or others if unchecked. And these experiences can lead to an existential crisis.³

I argue that, over time and on every level—within themselves and with family and friends, old and new—a young person's experiences with underaddressed mental health concerns diminishes their moral agency. Their moral agency needs to be replenished for them to move forward with their lives. Moral agency fuels self-confidence and helps others to have confidence in them. They need enough of it to become a valued adult who can be trusted to form and maintain relationships and make responsible decisions. It is crucial for well-being.

Nourishing others' sense that one is a moral agent, and thus nurturing one's own sense of moral agency, is hard for all young people. It is especially hard for young people with early psychosis. It's hard in part because of the lived experience of psychosis symptoms, which are disorienting in and of themselves, and in part because of our medical and societal ideas about and responses to psychosis. Not everyone experiencing psychosis ends up with a complete lack of moral agency at the end of the typical sequence of events. The initial breakdown, emergency intervention, psychiatric hospitalization, return home, and attempt to get back to "normal" all provide opportunities for both diminishing or replenishing moral agency. If we pay attention to these opportunities, we can offer more assistance during this difficult time to young people and their families and loved ones.

Ariana is one example of a person who found ways to start replenishing her moral agency right away. Ariana was trying—from the moment I met her—to protect her moral agency and establish her right to be seen as a good person capable of acting independently for the greater good of others. As chapter 4 relates, she immediately began exercising her autobiographical power by introducing herself to me as a person who volunteered helping children with learning differences in high school even as she was desperately distracted by voices telling her that the end of the world was at hand. When she returned home after a long-term stay at the county hospital and people started gossiping about her, she moved away—literally, quit her job and drove to another state—to take back control of the story others told about her life by starting over in a new setting.

Ariana's family was important in that process. Together, they used humor, trust, and love to help her move forward. Early on, they shared some laughs about her stint in the "crazy house" to help heal their relationship and reestablish the social bases of self-respect. Ariana used her relationship with her family to create a people opportunity for employment by helping her brother with his new infant while he and his wife went to work—a key source of material support for them both.

It was not completely clear that this would be enough to help Ariana restore her sense of moral agency outside her family and thereby transition to independent adulthood. Toward the end of our interviews, though, Ariana had this restoration in mind. She was considering the possibility of becoming a trained peer support specialist and having a career in helping others manage their own mental

health concerns based on her own lived experience of psychosis—which excited her. She wanted to get the certification needed for this position. Working as a peer support specialist seemed safe to her because it involved people who understood what she had been through and so offered her social bases of self-respect. Plus, she felt that it built on her skills working with children and youths with learning differences in high school. This could be just the peopled opportunity she needed to build bridges into communities of like-minded others beyond her immediate family.

If Ariana had continued to use psychiatric hospitalizations and medications to get better, her family may not have given her so many opportunities. However, by refusing antipsychotic medication and a psychiatric diagnosis of psychosis, both of which for her family were associated with being “crazy” or “addicted,” Ariana secured her ability to be seen as a good person. Ariana had a replenished sense of moral agency at the end of our study and demonstrated that upholding her status as a moral agent, at least for her, was more important than being medically compliant. A return to moral status that enabled her to belong was what she needed most at that time. It’s possible that if the medicines had not initially rendered her stable, she would have had another breakdown later—it’s hard to say. But while Ariana’s is a high-risk approach, especially in the absence of medical supervision, it made the most sense in her local moral world, and it would have been ideal if the care on offer—mutual support or a medical professional—could have partnered with her to help her recognize warning signs in case another psychotic break approached. In that case, if the onset of symptoms had been recognized early on, a low dose of medicine for the shortest possible amount of time could likely have kept her out of the hospital and firmly connected to her everyday life with work and family. That option was not offered to her, however, and we can only hope that she managed any future concerns with the help of her family and not another emergency hospitalization.

In contrast, Michael had very little sense that he could replenish his moral agency with anyone but his family throughout the study period. He felt stuck. His family begged him to leave the house, to sign up for an art class, anything. Michael refused. His mind, he was sure, did not work the same as other people’s minds. His thoughts felt more confused. Chapter 5 notes how he struggled with erectile dysfunction as a side effect of his antipsychotic medications (a common one).⁴ His ideas about success and masculinity and his potential as a health care worker or husband and father after a schizophrenia diagnosis seemed severely limited, which led him to doubt that he could ever have a career and family and belong in the adult world.

Michael did not recognize himself, as he explained: “I just don’t feel like myself. [. . .] I was going through my Facebook posts [from 3 years ago] and it just seems like I don’t even know who that is. Like, it seems like the real me, but I just don’t know who that person—it just doesn’t feel like it was me that did it.”

His family reassured him that they were still willing to see him as a moral agent even though he had tried to harm his niece when he was overwhelmed by psychosis. They were confident that while he was not quite himself and had not been for a couple of years, he was fundamentally a good person whom they loved. He had scared them, but he used their memory of him as a moral agent to move on with living together peacefully at home while refusing mental health care.

Michael's family did not want him to use psychiatric labels. They did not believe he had schizophrenia, and they thought that medication made him not like himself. When they initially sent him to the state hospital and followed medical advice, their friends were horrified and told them to get him out as soon as possible. Although Michael followed his family's directions, he struggled with the loss of his former social status, his virility (which did not come back right away when he stopped his medications), and his sense that he was a stranger to himself.

His family encouraged him to hang on to hope, but toward the end of our study Michael was still at home, had not been visiting with friends for a couple of years, and was not working or in school. He felt deeply disheartened. He was losing his sense that he could ever be a moral agent in this world. He thought maybe he could thrive in a place where there were only people like himself.

He explained:

I feel like I would be better off just with the schizophrenia if the government just had like an island, like—I don't know. Just took people with mental illness or schizophrenia, I don't know about bipolar disorder, but just put them on an island, and just let us live out the rest of our lives like that. If they'd have done that, I wouldn't even know the difference. I don't know. I think once your mind goes off reality, I don't think it goes back. I don't think the medicine that we have takes you—fixes everything—and takes you back to how you were before. I think it just like stops the symptoms, but like the other stuff you lose, I don't think you gain it back.

Clearly, for Michael, his local moral world was more important than medical advice. He did not trust the treatment on offer and his family did not, either. Most important, he needed to feel that he could belong somewhere in a way that was seen as at least good enough by those around him, and he did not see how a person with schizophrenia could live with anyone besides other people with psychosis—on an island where they could all be themselves.

Corrina used mental health treatment because her family required her to do so to be accepted back into their home. Taking medications did not fix everything. For months—and through five different medications with frightening side effects, including convulsions—they did not work. She had aggressive episodes and disappeared for hours at a time. Once the medications did start working, she still had trouble establishing herself as a moral agent in her family and in the world beyond her house and her boyfriend. The constraints on her moral agency were evident during our home visits: her well-intentioned mom was supervising her narrative,

controlling some of her autobiographical power. Her family remembered how she had been reckless and frightening and had not fully convinced themselves that Corrina was trustworthy, which limited her peopled opportunities and social bases of self-respect at home. It was hard to forget “Karina,” who thought they were demons sent from another galaxy and destroyed their property.

Corrina’s mother wanted her to finish her college degree. About half of the young persons we interviewed had at least some college education when they had their psychotic break. During the time she engaged with my team, Corrina tried to go back to college, but she did not have the confidence—and likely did not have the right accommodations and support—to return to school. Instead, she had a nervous breakdown in her college classroom, which further diminished her self-confidence and her willingness to practice being a moral agent in the outside world again. With few opportunities to replenish her moral agency at home, Corrina had trouble doing so in the outside world as well. Instead, she continued to live with her parents and hang out with her boyfriend and his friends watching Netflix and smoking cannabis. For her boyfriend and his friends, that was good enough, but that was not going to launch Corrina into valued adulthood.

Corrina was insightful and smart, and she had the potential to do more—she knew it and her mother knew it—but she was not sure what to do. One time she asked me shyly if she could sit in on my classes—maybe having the right professor who understood what she was going through would help, she thought. *Sure*, I said, though I had no idea whether SMU would allow it. But she never reached out to ask me again.

I have also shared the example of Markus, whose mother (or her God, from her perspective) was very much in charge of his narrative, leaving him little opportunity to work on his autobiographical power. For Markus’s mom, Hazel, having faith that God would heal him was more important than any medical involvement. She shared that medical involvement for mental illness was not acceptable for what they understood to be a “spiritual attack” (see chapter 5). Hazel was trying to preserve his social bases of self-respect by having him refuse medical care. She used the hospital only as a holding tank so that she could continue to focus on fasting and praying for his spiritual healing. Hazel said: He doesn’t need medical intervention but periodic advice, yes [. . .] to give him examples of, ‘Look at this person—he went to school, did this, and this is where he is so you too can do it.’” Hazel and Markus would likely have benefited from a peer support specialist who could have offered encouragement and advice on how to thrive after experiencing psychosis—the very kind of person that Ariana hoped to become.⁵

Ariana, Michael, Corrina, Markus, their families, and, really, most Americans have the same need: to experience life as a moral agent in community with loved ones who matter to them. Some people think of this as recovery. “Recovery” has been a popular movement in American mental health care, a movement that insists that people can get better—perhaps even better than they were

originally—even after they experience a serious mental illness.⁶ However, for young people, I am unconvinced that *recovery* is the right word. *Recovery* implies a cure or a return to something—a righting of a wrong. But a psychotic break is not a wrong turn at the crossroads, as James suggests in chapter 1. Rather, it is a moment of vulnerability and potential—an opportunity for a person to become diminished or replenished in terms of the moral agency they need to move forward with their lives—and that depends on the medical, moral, and material resources available to them, as well as their ability to procure them through intimate relationships based on mutual moral recognition that one can at least become a “good enough” person again.

. . .

There is no cure for psychosis, and it is not wrong to have psychosis symptoms. Some see it as a gift. For most of the young people I met, the psychotic break started off as an intense spiritual experience, which was not a negative experience. Some have called psychosis a spiritual emergency.⁷ There are many ways to describe the experience, and they do seem to matter, so what if, instead of a breaking point, a psychotic episode was considered a turning point on the pathway to adulthood? A point where loved ones and other adults capable of offering support realize that someone needs extra moral, material, and medical support and that we can and must offer such support to prevent negative outcomes and help them move toward a meaningful life? Such rethinking could also serve as a turning point for society: an invitation to families and the broader culture to help protect, promote, and replenish moral agency for all young people who are struggling to become valued adults and belong.

We can begin by doing more of what this book has been trying to do all along: holding space open for individuals experiencing psychosis and listening more compassionately to them. As anthropologist Luke Kernan writes, “To view these experiences as endpoints, as brief silences, or as something discrete and outside of their larger context, is dangerous both ethically and academically. They have sonic reverberations, consequence. And, as the night can fall fast, we should be astute and boundless in mobilizing agency and becoming—of injecting compassion into that lifeblood to assuage the burden of self. Of taking responsibility. Of listening.”⁸

This book is a product of my team’s best attempts to listen during the challenging critical period in the first several months after a person’s initial emergency hospitalization for psychosis. What follows are some ideas for social change and reform based on what we heard and what we know from the literature works. Here, I have done my best to draw together the evidence base for what works in order to provide steps we can follow to promote moral agency during a young person’s pathways to and through care and so reduce the negative consequences of experiencing psychosis in a society that, in general, offers few affordances for

nonconsensus realities. If we take these steps to turn what I identify as breaking points into turning points that signal the need for us to work together to protect and replenish a young person's moral agency, we will see many more youths returning to their pathway to valued adulthood.

STEP 1. PREVENTING BREAKDOWNS

Ideally, we would prevent a full mental and moral breakdown from happening in the first place. We need to offer material, moral, and medical support to young people, as appropriate, before they have gone too far down the road toward those “catalytic events” that call their moral agency into question: being dismissed from school; losing roommates; losing a job; threatening or harming oneself, a family member, or romantic partner; engaging in egregious substance misuse; wrecking a car—all examples shared in the young people's stories in this book. We have to offer people help *before* they get to that point. Many people delay seeking help for a mental health crisis. There are many reasons for this decision and many solutions.

We can start by recognizing that even when they may seem delusional, young people are trying to find a frame of reference via a locally available cultural mythos that can help others perceive them as good people worthy of relationships. Rather than telling them they are crazy or rejecting them, we might be curious about the identities they have chosen, such as a superhero, Jesus, or an angel. “I see you; I hear you; and how can I be supportive?” is always a helpful approach. If we do this more often, from within the morally meaningful cultural spaces that people naturally seem to seek out during a psychotic episode, such as religious spaces, we might help people find meaning in their psychosis experience in ways that are gentle, do not induce fear and isolation, and gently nudge them toward connecting with further medical and material support. This approach would require us to think carefully about what cultural toolkits, such as those mentioned in chapter 2, can help people make sense of their psychosis in a more life-affirming way. While I understand that some people may end up thinking they are Satan or a demon, I suspect that this happens when others reject or ridicule them and they become confused and self-deprecating. Social media both exacerbated ideas that persons were communicating with them when they were not, as with Pedro's Liquor Ladies, Miranda's Romeo, and James's celebrities. It also opened the young person up to criticism, as Sage and many others explained, leading many of them to later regret posting anything online when they were experiencing symptoms. Some, including Michael, withdrew from social media, which could be isolating. Others kept posting things they later regretted, leading them to leave online life, as with Corrina.

What I noticed in my research was that if a young person's psychosis experiences were interpreted negatively by others, the person became afraid, began to

isolate themselves more, increased their substance use (typically cannabis, which many thought helped with anxiety), and lost too much sleep. Each of these results seem like something we can prevent.

*Mobilize Faith-Based and Community Supports to Address
Help-Seeking Delays*

In my research, religion and spirituality constituted a widely used source of cultural mythos for young people trying to make sense of psychosis. I am confident that with good training and care we can work with pastors, priests, imams, chaplains, rabbis, and other faith-based leaders to craft cultural toolkits that support young people and can potentially prevent a crisis.⁹ Training faith-based leaders in mental health care has been done in other parts of the globe where there is a shortage of mental health professionals,¹⁰ but there is no reason not to try this in the United States, especially in areas with limited mental health care and in communities that identify as more religious.

In my own small research study in partnership with Valerie Odeng, a public health master's student and Black African immigrant, Valerie interviewed 17 Black African immigrant pastors in north Texas after sharing a vignette with them about a person with early psychosis.¹¹ We found that the pastors were very eager to receive further training to help. All the pastors we talked to thought relationships were key, whether they involved partnering with young people, families, or health professionals. Faith-based leaders can foster a communal form of alliance that includes the families of the person experiencing distress and takes place in nonclinical, likely less stigmatizing settings such as in the privacy of the young person's own home or at their church. This may be especially helpful for a young person's sense of moral agency—protecting and replenishing them as they go along—before they fall into a crisis.

Faith-based leaders also have a pre-established level of trust with congregants that may make it easier for them to advocate for certain kinds of care (such as psychiatric attention) and engage families and persons with mental health concerns more effectively than others. This trust could be a good supplement for other kinds of social services, especially in rural or impoverished areas with fewer resources or for cultural groups that might respond better to a trusted community member than to a less familiar mental health professional.¹²

The pastors my team engaged with also expressed a strong desire for further collaborations with other mental health professionals. At least one pastor mentioned sending chaplains to offer support to the local mental health system. Licensed chaplains are found in hospitals and schools (most often higher education), as well as military settings.¹³ They have helped the Department of Veterans' Affairs support people experiencing moral injury in the context of posttraumatic stress and may also be an important care resource for people with psychosis, who often have trauma histories.¹⁴ Working with churches, synagogues, mosques, and interfaith

chaplains to provide spiritual support to persons with psychosis and their families could also help nourish moral agency. Since many people have experiences they identify as spiritual or religious, and since those people often approach religious or spiritual leaders first, it makes sense to offer these spiritual leaders training in how to support, screen, and refer young people who may be in the early stages of a crisis. In partnerships with Black faith communities, mostly in the urban United States, this approach has met with some success in reducing mental health stigma and addressing mental health concerns such as depression, though the studies we have thus far have been limited.¹⁵

It is important for young people to access mental health support as soon as possible after symptoms first appear. One way to encourage young people to seek out help more quickly is to reduce the stigma around asking for help. For example, Ariana waited a long time to go to the “crazy house” because, in her Hispanic culture, a person is either fine or “crazy.” There is no in-between. I have heard people from rural America express similar ideas. There are things we can do to help people think of mental health care as a positive solution, not a signal that someone is “crazy” and therefore outside the range of acceptable human experience.

It seems to me that the families in the study provided a lot of guidance on how stigma-free early intervention might make sense for them. They wanted control over the labels, especially given their impact on the young person’s moral agency. Families and young people tended to use more culturally acceptable, common-sense terms, such as *nervios* (literally, “nerves”), PTSD, or depression, which may be more acceptable and easily recognized. These terms may not convey the seriousness that *psychosis* or *schizophrenia* signal, but it left families and young people freer to speak openly about what was going on at a vulnerable time. Using more flexible sets of information and diagnostic terms may also help ease medical mistrust in communities that have experienced mental health measures as forms of social control, such as the African American community, where the diagnosis of “schizophrenia” has historically been used to lock up Black civil rights activists.¹⁶

In addition, young persons and families who did seek help prior to an emergency tended to approach trusted community members first. Following their lead, we can listen to and build partnerships with key supporters that young persons and their families do trust. For both Latino and Black participants, as I have mentioned, faith-based leaders were often trusted advisers. Other potential community partners include school counselors, teachers, coaches, and librarians. Alternative healers such as *botanicas* or *curanderas*—visited by some of our Latinx participants—may also be trained to help families recognize when a young person may need more support. Every possible community partner needs to be trained to informally support young people and families as mental health concerns develop, and then to guide families who need help to connect with more formal forms of support as early as possible.

Reducing help-seeking delays demands that we work with families, especially in public school settings, to make sure they understand that mental health is as important as physical health, and that we help families, teachers, counselors, and coaches recognize warning signs that a young person may be struggling. I think of this as a young person's *care network*—the people who might be linked together to support a young person when things start to go wrong. It would be crucial for multiple people in a young person's care network to have the knowledge and ability necessary to quickly recognize when things start to go poorly. This preparation is always complicated: how do we provide education and training that avoids increasing stigma around certain children and youths, just as we do with those who are struggling in other ways? However, if done well, having well-developed community-based supports for youth mental health can help families avoid catalytic events, police involvement, and emergency interventions, which in our study were always damaging to the young person's moral agency.

Educate Frontline Prescribers about Psychosis

That a young person has accessed mental health care does not mean that care they're given is the best for early psychosis. It is ideal for the psychiatrist on the care team to be someone the young person likes. However, there are not enough psychiatrists available—about half of Americans, 150 million people, live in federally designated mental health professional shortage areas.¹⁷ Thus, there are many different prescribers of psychiatric medications, including general practitioners, nurse practitioners, and physician's assistants, and not all prescribers have the training needed to help with psychosis. For example, negative symptoms of psychosis such as attention deficits and working memory loss may be misrecognized as symptoms of ADHD. One recent survey of 140 college campuses found that 1 in 6 students reported a psychotic experience over the previous year. In those cases of psychosis symptoms, use and misuse of amphetamine-based drugs like Adderall prescribed for ADHD (and several other prescription drugs) were associated with mostly mild (but noticed) psychotic experiences after adjustment for alcohol, tobacco, and cannabis use.¹⁸ More research is needed to understand the relationships between prescription amphetamine use or misuse and psychosis. Meanwhile, any prescriber who is not intimately familiar with current information on psychosis may not know the risk.

In addition, not all prescribers know the best practices, which include prescribing a person experiencing a psychotic break the lowest possible dose of antipsychotic medications for the least possible time so as to avoid, as one psychiatrist told me, “using a fire hose to put out a candle.”¹⁹ Overprescribing can turn young people like Sage off to using medication completely. Antipsychotics are also sedatives and so, at higher doses, make work, school, and social activities more challenging. In addition, they do not work for everyone. Prescribers

need to be trained specifically to understand which drugs can trigger psychosis: who is at risk; how to recognize and help when a person is developing psychosis, including from a drug they have been prescribed; and when to refer a person who is struggling to a psychiatrist—preferably before they go into the hospital for emergency treatment.

Ideally, there would be a national network of psychosis-specific psychiatrists able to treat patients via Telehealth across county and state lines so that young people with psychosis everywhere have access to the best prescribers for their concerns and the same prescriber over time, regardless of whether they are at home in a rural area, attending school in another state, studying abroad, traveling with the military, or doing a summer internship (or, say, during a global pandemic). However, developing this network would require addressing barriers to receiving mental health treatment across state lines and issues with computer and internet access in impoverished or rural areas.²⁰

Substance Misuse

While we are at it, we need to address one of the main issues for young people with early psychosis, which is that substance use—so popular in American culture for young people—can complicate their symptoms and lead to more aggressive behaviors. Many young persons could benefit by not “playing” quite so hard. There are other ways for young people to connect besides partying together, and we need to build up both those points of connection and opportunities to help young people decide to stay sober or engage in healthier activities together. I loved Pedro’s idea of offering more gym memberships to young people who otherwise lack the resources and who would find wellness and community in that kind of space.

Another possibility would be to increase the availability of youth-focused events—open to the wider community—at explicitly “sober” spaces where young people already naturally enjoy hanging out, such as coffeehouses. Activities could include poetry slams, open mic nights, film screenings, book clubs, “knit ins” for people who like to knit or crochet, video game competitions, and so forth. Such activities could be fun, provide for a creative outlet, and build community. These activities could also be offered in churches, public libraries, or other community spaces like the local YMCA. Evidently the app “Phoenix” helps people connect in just such a way in communities across the United States.

Creativity was also an important resource for the young people in our study. Even though the interview protocol did not prompt young people to talk about it specifically, one-third of the young persons we interviewed mentioned making music or pursuing visual or performing arts. Research indicates that interventions that reflect the culture of a target population are more effective than standard treatments.²¹ Using rap or hip hop as a base for developing new interventions, for example, could offer fresh ways to engage youths who enjoy those kinds of



FIGURE 7. “Songbird” by Joseph Steven Lorenzo. This image was a gift from my younger brother to celebrate my husband’s love of music. Joseph texted my mother a note to accompany the image in this book: “People with mental illness have the gift of seeing and imagining things differently. This is expressed in their art.” My brother has been making art for more than thirty years. *Reproduced with permission of the artist.*

music. Fun activities—and the friends that can result from having something in common—are also helpful for replenishing moral agency.

STEP 2. IMPROVING CRISIS MANAGEMENT

The current pathways to care that most young people have available to them—typically after a crisis, through an emergency setting, and often with police involvement—set young people up to fail. Such a pathway invites social stigma by making an early mental health crisis seem criminal. It exposes young persons to confrontation with and possible physical harm by the police. It sets them up to have a police record, incur court costs, and face other challenging criminal justice outcomes that can tax their material resources and meaningful relationships. As a result, the young person and their families seriously question their moral agency in the days that follow. As a society, we must decide, Are they “mad” or “bad”? What do we mean by those terms? What are the consequences of the approaches we use? With this information, we can work toward reform. In the meantime, here are a few places to start.

Even within a supportive community, and even when there is some mental health care in place, families still may need emergency services. Unfortunately, the way most families know to contact emergency support is to call 911. As soon as that happens, the police are also notified. In twenty-eight states, police are legally required to be involved in an emergency call. But police involvement is often highly visible to neighbors, families, and friends and perpetuates the impression among all involved that they have done something wrong or even bad. The optics and consequences of police involvement, including the reputational and physical danger to people in crisis, need further attention. Simply put, if a person is experiencing an emergency, we could provide gentler entry points to care.

One initiative includes the number 988, which connects people to a mental health crisis hotline with access to trauma-informed counselors, mobile crisis units, co-responder services, and longer-term mental health programs. Since the line replaced the National Suicide Hotline in July 2022, the numbers of calls, texts, and chats have risen by 45 percent, with 80 percent of calls answered by someone in the same state, 93 percent of calls and 98 percent of texts and chats being answered overall, and reduced wait time to talk to a counselor.²² Currently, however, there is concern about insufficient mental health resources like a counselor on call, a safe or respite space available where people can go, or even knowledge of local resources when they do exist among persons staffing the lines, as well as questions about the training and qualifications of 988 staff in general.²³ In addition, not all calls are answered, it is not clear or uniform how 988 works from region to region (some states have significantly lower answer rates, such as Arkansas and South Carolina at 55–69%), and the waitlist for many

mental health services to which a person could be referred is far too long. It took a while to work the kinks out of the 911 emergency system, and even that still has issues, and proponents of 988 argue that it will take sustained effort. We need to make sure people keep trying to make this emergency number work more efficiently at the local and the state level.

For the time being, police will likely continue to be the primary first responders to psychiatric emergencies in most states. Interventions to improve police interactions include the use of mobile crisis clinicians, unarmed response units, and mental health–trained intervention teams.²⁴ Even police officers who receive only a special 40-hour training about mental health as mental health first responders (crisis intervention team [CIT] model) are more likely to offer a person mental health services (instead of jail) and less likely to use force and arrest during police encounters with individuals with a mental disorder.²⁵ To date, more than 3,000 jurisdictions worldwide have implemented this CIT model.²⁶

Other models use co-responders and embed a person with lived experience, a social worker, or a behavioral health specialist in the unit that responds to mental health emergencies. People in crisis prefer this model.²⁷ Dallas County, for example, has piloted such a program, the RIGHT Care program, since 2018. The team includes a community paramedic, a licensed mental health clinician, and a specially trained police officer. According to its website, the team responded to 4,000 calls in the first eighteen months of its existence, with only 2 percent resulting in arrest, 900 people being diverted from the emergency room directly to mental health support, and 500 diverted from jail. Whether it has been deemed to have worked well in the long run or will be expanded remains to be seen.²⁸

There are alternatives available, but as a society, Americans need more investment in pilot programs, developed in partnership with the communities expected to use them, to understand what works well, for whom, and under what circumstances. Interestingly, the least-restrictive options, such as a crisis line or mobile crisis team, are also the least costly but need to be more widely available and able to connect people to mental health supports and services quickly.²⁹

STEP 3. REDESIGNING EMERGENCY HOSPITALIZATIONS

Ideally, young persons experiencing early psychosis would never reach a crisis point where they are being brought into the hospital by police. Expensive emergency hospitalizations offer little material, moral, or therapeutic support and are a far cry from psychologist Carol Gilligan's notion of ideal care as "an activity of relationship, of seeing and responding to need, taking care of the world by sustaining the web of connection so that no one is left alone."³⁰ In fact, being left alone is often what happens to young people with early psychosis, as friends, family, educational

structures, social networks, and vocational opportunities evaporate after they have been picked up by police, hospitalized, and deemed “psychotic.”

We desperately need to redesign our approach.

Educate Providers and Families about Privacy Laws

First, it might greatly help if young persons and their families could be better connected with each other during their hospitalizations and subsequent experiences with bouncing, especially when everyone is new to the system. To better ensure connection, we need a widespread understanding about what HIPAA laws mean and what mental health professionals can and cannot tell families when their loved one is in the hospital, in jail, or the like.³¹ Often institutions of care assume they cannot share *any* information, but this is not true. In a whole set of circumstances, family members are permitted to know about the care of their loved one in psychiatric emergency situations, as recently outlined in a document from the Office of Civil Rights of the US Department of Health and Human Services.³² For example, a family can be notified if the patient has not objected, if the family has been involved in care previously, and if the hospital staff can infer from surrounding circumstances that it is in the best interest of the patient (for example, the patient did not describe abuse at the hands of a parent). If a patient is unable to agree or object, because of some incapacity or emergency—which arguably applies to some of the young people in this study—then a psychiatric hospital is free to notify a “member of the household, such as a parent, roommate, sibling, partner or spouse, and inform them about the patient’s location and general condition.” A hospital can also “disclose the necessary protected health information to anyone who is in a position to prevent or lessen [any] threatened harm” if such disclosure can reduce a serious and imminent threat to the health or safety of the patient or others, even without the patient’s agreement.

This last clause is the key that might have helped Daphne and others, though it leaves a lot of room for interpretation. In fact, the law even states that no one can “second guess a health care professional’s judgement,” and so they are free to share when, in their judgment, sharing may protect the patient from harm. Therapists can even contact parents to let them know that a patient has not been attending appointments and may be in danger. These circumstances need to be made clearer to the public and to institutions of care so that young people aren’t getting lost in the system while they are bouncing between facilities or after discharge. In many of the examples I share in this book, key supporters needed access to more information about the youths’ whereabouts and well-being but were unable to get it, possibly because health care professionals did not understand the spirit of the law or feared receiving hefty fines or being sued.

Some argue that the law is often interpreted incorrectly by health care facilities or by employees without adequate training (who are often on the frontline

interacting with families), which prevents patients' families from getting information that is not actually restricted under the law. Some doctors are calling for the laws to be revisited to address unnecessary bottlenecks in patient care. In cases of early psychosis, better connecting parents to the hospital and to other mental health providers may go a long way toward helping keep a young person safe (assuming that the family is a "safe space" for a young person in the first place, which was true for most of the young people in our study).

Focus on Trauma-Informed Care

Given ample evidence that people seeking inpatient psychiatric services have often already experienced trauma, it seems clear that traumatic histories affect a person's willingness to seek help and engage in care.³³ As Sascha DuBrul advised, "We desperately need to create sanctuaries for people who are having the kind of spiritual and emotional crises I was having when I was a teenager."³⁴

One approach is to implement principles of trauma-informed care in emergency settings and among first responders for people in crisis. Maxine Harris and Roger D. Fallot, former codirectors of Community Connections, an addiction and mental health rehabilitation program in Washington, DC, identified five principles to guide trauma-informed care practice: physical and emotional safety, trustworthiness, choice, collaboration, and empowerment.³⁵ Physical and emotional safety includes separating patients by their self-identified gender at all stages of care,³⁶ making safe "time-out" spaces available, respecting patient privacy and modesty (when they are bathing, sleeping, and using the bathroom), training staff in de-escalation strategies, and helping patients identify triggers and calming strategies to help them feel in control. Establishing trustworthiness includes helping clients feel safe, respecting their emotional limits, explaining procedures and tests, respectfully and consistently practicing informed consent, and maintaining respectful professional boundaries. Collaboration means treating the client as an expert on their own life and allowing the client to plan and evaluate the care they receive. Finally, empowerment refers to helping clients identify and employ coping strategies. For services specific to early intervention for psychosis, research suggests that trauma-informed care involves seeking agreement and consent from the service user before beginning any intervention; building a trusting relationship with the service user; maintaining a safe environment for service users; fostering a calm, compassionate, and supportive ethos; and being empathetic and nonjudgmental.³⁷ While these principles may sound like basic human kindness, some of the stories I have shared throughout the book suggest that this is exactly what needs to be upheld as important in emergency psychiatry settings. Many of these elements were missing from the care the young people described receiving, and following any of them may have made a difference for preserving and promoting moral agency. Research suggests that conditions are not better elsewhere

in the United States.³⁸ Changing these conditions will require time, training, and commitment.

Safe Spaces for Mothers and Children

My research also revealed that one group in dire need of better solutions is young mothers with early psychosis and their children. Nursing mothers faced the added physical and psychological challenges of stopping breastfeeding.³⁹ In the United Kingdom and other countries of Western Europe, there are mother-baby units that keep mothers with postpartum psychosis and their babies together with a focus on safety, psychosocial support, and psycho-education. However, this accommodation was nowhere evident in my study, and one advocacy group, the Maternal Mental Health Leadership Alliance, wrote in 2023 that only four such units exist in the United States.⁴⁰ My team did not witness anyone even offering a breast pump to a nursing mother.

One group that may have an experience comparable to that of mothers dealing with psychosis is incarcerated mothers. Research on this group suggests that forced separation of mothers from their children is an experience similar to stillbirth or miscarriage and increases the risk of self-harm as the woman struggles with the loss of their identity as a mother.⁴¹

Separation is hard on the children, too, and can have lasting consequences. First, breastfeeding, when possible, is essential to infant development. Second, the cycle of institutionalization seems to perpetuate itself. Women with a psychotic disorder who had their children taken away from them while in a joint mother-baby unit in France and Belgium for women with postpartum psychosis were 4.4 times more likely to have been separated from their own mothers and institutionalized as a child.⁴² Children who are separated from their own mothers and institutionalized thus may be more likely to have their children taken away later. The research recommends that, if separation is necessary, the child be placed with a family member or a foster family rather than in an institution to help limit the consequences of maternal separation for the child.⁴³ This is an area in need of careful consideration and reform to stop the devastating cycle.

Value and Offer Mutual Supports

Many, many times throughout this research (and in my global health work as well), young people and their families expressed an interest in working more with someone who had been through psychosis as a young person and was now doing fine. Such people are known as peers or peer support specialists. A peer is someone who understands, someone who has been there before, someone who is doing well. For youths and families, they also wanted this living example that things could get better. Employing more peer support specialists in emergency and crisis services can help improve the system and promote moral agency, because peers

can serve as real-world examples of the fact that, though a person may be having a hard time—including homelessness, substance use disorders, and incarceration, along with serious mental health symptoms—they can still pass through it and find meaning and purpose, gainful employment, and community in a group of people who have survived similar experiences. Peers can also offer advice to young people about how to manage symptoms and medications, relationships with therapists, psychiatrists, friends and family, resources for wellness, and much more. Several young people I talked to said they would happily volunteer to visit other young persons in the hospital to help them know they were not alone. This would probably be possible via Telehealth, as well, which may help reduce concerns about safety, anonymity, and the possibility of accidentally triggering someone by sending them into the hospital as a volunteer. Some, like Ariana, already had plans to become a professional peer support specialist. A support group composed of a mix of people who are struggling and people who are doing well and can understand and encourage one another could be ideal.

These kinds of options do exist, just not in formal mental health care settings, typically. One is the Hearing Voices Network, run by people who share the experience of voices, visions and other extreme states.⁴⁴ Another is the Fireweed Collective, for persons who identify as mad or neurodivergent. The Inner Compass Initiative seeks to empower people to make a friend with someone who is having similar experiences and claims to offer unbiased, straightforward information about psychiatric drugs and diagnoses. Some of these groups hold gatherings in numerous local communities around the United States (and other countries) and online to help people, in mutually supportive ways, manage experiences such as hearing voices and taking or tapering off of antipsychotic medications. The Wildflower Alliance, with support from the state of Massachusetts, has four community centers, operates the peer-run respite Afiya House (mentioned earlier), and also offers training workshops for people seeking to deepen their peer support skills. DuBrul, who started the Icarus Project, which turned into the Fireweed Collective, explains that mutual support networks make friends into everyday heroes who are accessible on a local level: “We send off ripples” of support, he observes, “through the fabric of our friends.”⁴⁵ This network building provides more community, he explains, so that people do not spend their whole lives feeling out of place.⁴⁶

Corrina similarly said:

If these [other young people in my study] don't have a lot of friends, which, it can be hard . . . That makes it ten times worse, so much worse, and then that also puts more strain on the people that are in their family, 'cause they become more needy, 'cause you need friends. I realize now, without my friends, I feel so depressed and so much more anxious. If y'all needed to get me in touch with any of these people, I would be willing to talk to anybody, because I understand if they need a friend, I can be a friend.

While confidentiality issues prevented us from connecting the young people in the study, Corrina would have been a valuable friend for a lot of the young people my team met. She herself made a few friends in group therapy whom she stayed in touch with for support. Young people are making such friends organically, but more of us could, and should, help them along.

Alternatives to Inpatient Hospitalizations

Another possible approach is to divert “first-timer” young people away from emergency hospitalization altogether to smaller, safer spaces. *Peer respites* represent one such alternative, so called because they are staffed by peers. Peer respites are typically run out of houses in residential neighborhoods and serve as places where people experiencing a mental health crisis can go any time of day or night for a short-term stay (an average of five days in 2018⁴⁷) as an alternative to psychiatric hospitalization.

Peer respites provide services such as support groups, one-on-one time with peer specialists, recovery-oriented self-help training, and recreational activities. Many respites allow people to stay who are actively suicidal or experiencing psychosis, or both, but admission is determined on an individual level.⁴⁸ They also permit people to choose whether they want to take medications, and they offer a safe space for those who do not. Currently, there are thirty-three peer respites in thirteen US states.⁴⁹

One randomized clinical trial comparing the use of peer respites to locked inpatient psychiatric facilities among a sample of uninsured, civilly committed adults found that those using the peer respite self-reported improvements in mental health and treatment satisfaction.⁵⁰ A study of the effectiveness of another peer respite program in New York found a reduction of 2.9 psychiatric hospitalizations per respite client as compared to clients who went to the emergency room in the first year, and Medicaid expenditures were an average of \$2,138 lower.⁵¹ In a qualitative study from the Southwest, peer respite users described the first two days of their five-day stay as a time to slow down and rest and the last two days as preparing to reenter their daily lives. Users thought the peer respite created a “much more relaxed atmosphere” than a typical psychiatric hospitalization,⁵² though a minority did not like the unstructured environment.⁵³ In a matched-pairs analysis between patients who used peer respites and those who didn’t, people who went to peer respites instead of the emergency room were 70 percent less likely to end up in inpatient psychiatric hospitals.⁵⁴ I wonder if this has something to do with the Medicaid reimbursement rules for emergency rooms that seem to encourage long-term holds in inpatient facilities to protect reimbursement for uninsured patients, a practice I detail in chapter 4.

In another qualitative study of people who have used peer respites, most concluded that being around peers who have been through similar experiences was

comforting and helpful to their recovery. Afiya, a peer respite center in Massachusetts, conducted poststay surveys suggesting that it was greatly beneficial. Ninety percent of participants said they would choose Afiya again over a hospital or other support option.⁵⁵

Many details are still to be worked out, such as the ideal length of peer respite stays. Many participants in one peer respite said that even a 30-day stay (this setting offered 3 to 29 days) would not be long enough.⁵⁶ Some who like peer respites don't want to leave, or may come back frequently, for example to avoid homelessness. Shorter stays likely helped people get back to their lives more quickly, but it's complicated. Some people need more sanctuary. Thoughtful training and supervision of staff and clients are also necessary, especially to prevent staff burnout.

The truth is that we know how to create the sanctuaries that DuBrul said he needed as a teenager. We know how to provide better emergency care for people with psychosis that is trauma informed and safe and offers mutual support that can protect moral agency. For a young person to want to continue engaging in further mental health care, the initial landings in "care" for them need to be soft, welcoming, and safe. American society needs to invest in more trauma-informed care and peer support in emergency settings, as well as alternatives to those settings, such as peer respites. We also need to build better support systems for mental health care workers. This includes training for the hospital workers who are trying to make meaningful changes in the face of arcane and difficult medical billing practices and a lack of structural or trauma-informed supports. Change for the better also means giving peers more opportunities and funding and space or bandwidth to provide support, both in the hospital and in the community.

STEP 4. OPTIMIZING EARLY INTERVENTION

Coordinated specialty care (CSC), as mentioned in this book's introduction, has been rolled out as the premier model of care for early psychosis intervention in the United States. Efforts to implement this model had barely begun in Texas when I first started my research, and no one in my study qualified under the initial eligibility criteria, which have since changed.

As these services have become more available nationwide thanks to federal and state investments in early intervention for mental health, much research and hard work has been done to decide what early intervention means (do we screen at-risk youths and pretreat?), what to offer, and how to best roll these services out to Americans across the country who come from a wide range of social contexts, levels of resources and need, and cultural backgrounds. At this writing, I am participating in one CSC research project called EPINET-Texas, funded by the National Institutes of Mental Health, which uses a "learning healthcare system" to create feedback loops with providers, youths, and families that can help us

optimize services. EPINET-TX is also in conversation with several other, similar programs around the country to harmonize data and learn more about what works and does not work for all Americans.⁵⁷

While much is shifting and being learned, in general, the model aims to offer some specific components in every location, including medication management, individual or group therapy, family psychoeducation, and vocational or educational support.⁵⁸ Of course, not all states fund these programs adequately, and not all young persons can access all of them, but since the model is currently considered to be an ideal form of care, I offer recommendations relevant to each of these components.

Medication Management

Once a person is diagnosed with psychosis, the way forward with medication must be thought through very carefully and in partnership with the youth and their family. As this book argues, medication management is a medical, material, *and* moral issue. Of course, young people need to be able to afford and access prescribers who know how to handle psychosis symptoms well with the right medication, as mentioned in step 1. But we also need to understand that the young person or their loved ones may not view using medications as a tool to help them replenish their moral agency and so they might reject those medications. Ariana's family and coworkers thought using medications signaled she was "crazy" or an "addict" or both—labels that she could not embrace—and so she refused longer-term medication use. Michael's sense that the side effects might limit his ability to be a father was too much to bear because, in his local moral world, becoming a father was key to meaningful adulthood. In contrast, for Pedro, using medications indicated that he might obtain disability income that could help the family, so he embraced medications—but on his own terms, making it clear that he was taking the medication to treat his PTSD, another signal to his community that his diagnosis did not mean he was a bad person. Amy—whose grandmother had died in a state hospital after being held there for schizophrenia—eventually embraced her medications because her family saw it as a way for her to avoid the same fate. Sage's grandmother had also been hospitalized for schizophrenia, but her parents and grandparents supported her refusing medications (though she did not refuse Adderall). At this point, the decisions the young people made about treatment depended on whether they thought using them to access a better life would not jeopardize the respect they needed to thrive from the people they loved.

Most research to date has focused only on whether people should have antipsychotic medications at all. While these findings are hotly debated, people who take antipsychotic medications their whole lives appear to live on average twenty-five years less than they might have, even when controlling for lifestyle factors like smoking and obesity.⁵⁹ The side effects of the drugs may contribute to cardiometabolic problems that can lead to heart disease and diabetes, for example.⁶⁰

On the other hand, a systematic review of studies exploring use of antipsychotic medication by people diagnosed with schizophrenia (which is not the inevitable outcome of early psychosis but is a possibility) claimed that mortality rates were higher in patients with no antipsychotic use than in those who did not use the drugs.⁶¹

Specific to early psychosis, a Finnish twenty-year follow-up study on discontinuation of antipsychotics following a first episode found that people who never used antipsychotics past their initial hospitalization had a 214 percent higher risk of death than those who did.⁶² Based on this evidence, the authors argue that long-term antipsychotic treatment is associated with increased survival. In Norway, some psychiatrists are encouraging medication-free options for early psychosis. One study that included interviews with patients who discontinued antipsychotics at different time points showed that a robust relationship with the treatment team, as well as patient personal responsibility and agency within that relationship, was imperative for positive outcomes after discontinuing medications.⁶³ Those who discontinued medication also described an improved relationship with their therapists compared to previous experiences. Yet discontinuing or not using antipsychotic medications is controversial, even among Norwegian psychiatrists.⁶⁴

There are many studies and arguments on both sides, and we do not have all the answers yet. Coordinated specialty care, the popular model in the United States right now, advocates for using the lowest possible doses of medication for the shortest possible time.⁶⁵ In a recent review, this CSC approach to medication prescription was associated with more work and school involvement among the young persons and lower symptom severity.⁶⁶ With my own results in mind, it seems clear that prescribers should, at a minimum, be taught how to interact flexibly and ethically with young people and their families concerning medications. Clear information about psychiatric medications, the side effects, interactions with other drugs, and whether they need to take a drug for life is surprisingly hard to find, and many people are receiving prescriptions without a clear sense of what the medications do. There needs to be more transparency around potential risks and side effects—a stronger good-faith effort to provide “informed consent.”

Decision making about prescriptions and changes works best when it is shared between patient and physician, which also ensures that the patient takes their medications as prescribed. Sofia was not interested in taking medications until she worked with someone who understood that she was experiencing “nervios” and needed homeopathic approaches alongside psychiatric medications. Furthermore, those who have unwanted side effects but no information on how to mitigate them often reject the medications. If antipsychotics are not helping them restore their moral agency by helping them look good, feel good, and be productive—all culturally valued states of mind for young people—then they are an unappealing choice. These suggestions line up with literature that advocates for “shared decision making” between doctors and patients as a key to ethical psychiatrist-patient relationships, but the connection should hold true for the young person and any

prescriber, as well.⁶⁷ Providers also need to be open to the possibility that psychosocial interventions may be more acceptable to a young person and their family.

Vocational and Educational Support

Vocational and educational support is another key part of the CSC model, but may not always be implemented, at least in public insurance settings where there are limited resources and staff. However, this piece is important in attracting young people to using early-intervention services. All of the youth in our study were highly focused initially on getting their lives “back to normal,” or at least back on track, and the best way to do this is to help them stay as connected to school and work as possible.⁶⁸

While nearly everyone in our study reported having employment during their lifetime, it is not clear that they all had a job they wanted or that paid well, and several lost their jobs during their crisis. In the state-of-the-art (but not yet widely available) CSC model, members of a team that supports a young person with early psychosis include “supported employment specialists” who are dedicated to helping young persons find a competitive job. In turn, young persons must choose to participate, use mental health treatment, and have a goal of competitive employment.⁶⁹ Supported employment programs then offer personalized disability benefits counseling and aid in a job search that meets the young person’s preferences. Participation in early psychosis services has also been found to increase work participation.⁷⁰

Educational support is another important goal for many young people as more Americans enroll in college after high school (70 percent in 2009) as an important part of their transition to young adulthood in a country where “college for all” is a widely held cultural ideal, though some media outlets argue that this ideal is changing.⁷¹ Supported employment programs can also offer education components. In one program that made quarterly assessments, OnTrack New York, having educational support in the first quarter in which young people were enrolled in services was significantly associated with school enrollment in the second quarter and continuing throughout the first year of services.⁷²

Overall, developing educational environments that better support people with mental health concerns stands to benefit many young people. One study found that over four-fifths of college-enrolled students experiencing a first episode of psychosis also face a disruption in their college education. While many return to college afterward, it takes them about a year and a half on average to do so.⁷³ This is a long time for a young person to be out of school. Smoothing the transition from the hospital back into school or preventing a full disruption in the first place needs to be a high priority. Back-to-school toolkits for higher education, developed for students and families as well as administrators, suggest that effective accommodations create more inclusive environments and offer more flexibility around helpful forms of testing, attendance policies, and classroom resources (e.g., recording lectures).⁷⁴

Stigma is also a huge concern in higher education. Administrators, professors, and teaching assistants are not sure what to do with a student who is having a mental health crisis in class—or afterward. I have seen this personally as an educator. It can be difficult for students to access mental health care while on campus or back at home during a break. Students like Pedro, James, Sofia, and Markus shared their problems with school expulsion and student loans related to their mental health crisis. James was expelled from school. Corrina had to drop out due to the anxiety it caused her to attend classes. All of them lost scholarships and financial aid and had loans they could not cancel because they had passed an administrative deadline at the school for withdrawing. Young people were then carrying debts even though they had no course credits or progress toward a degree to show for them. We need to develop more compassionate policies and evidence-based guidelines to support young people in staying in school, not penalize them when they cannot, and to help them get their student fellowships and scholarships back when they are able to return.

Counseling centers also need to be prepared to help young people with psychosis or make referrals to people who can, and student insurance needs to cover that care. We could create technological options for young people who need to attend school virtually for periods of time to manage serious symptoms. My favorite option comes from Norway, which has pioneered using “telepresence robots” that can attend class, record lectures, and take notes for disabled or sick children when they are not well. The program has met with some success—but, of course, not without some controversy.⁷⁵ Why not pilot such a program here for young people who require long inpatient stays? Or at least have someone—perhaps a teaching assistant, a school employee, or a student volunteer—record lectures and take notes for them? These are not expensive or complicated asks. Someone just needs to care enough to make it happen.

Supporting Families

Throughout this book, I show families that were often a key part of protecting, replenishing, and nourishing a young person’s moral agency. They also provided critical support of a young person materially (providing housing, cell phone payments, food) and medically—for example, by given them a safe place to stay, reminding them of appointments, providing transportation, and monitoring medication use. Most people working in early psychosis services seem to believe that involved families are the best possible asset for a young person in their recovery. But to be able to provide material, medical, and moral support effectively, families themselves need sufficient support.

Most CSC programs offer “family psychoeducation,” if anything, but much more is needed.⁷⁶ Family psychoeducation is important; it is meant to help families understand what is going on with the young person and how to support them by increasing their “mental health literacy”—a construct I critique in chapter 3.

However, none of the families I met accepted the psychoeducation on offer. In general, I think there must be longer, more in-depth, and more sustained family support for families to heal.

Some innovative programs are using “family navigators” or “family support specialists,” people who have a loved one who has experienced a serious mental health concern and so are able to offer a lived-experience perspective as a family member to those newer to the experience.⁷⁷ One study from Australia found that family peer support workers who provided families with comfort, guidance, and advice were helpful.⁷⁸ In my own research on the “Opening Doors to Recovery” program in Savannah, Georgia, my team found that family community navigation specialists—as they were called in that context—were a positive addition to a team of supporters for persons with long-term psychiatric disability.⁷⁹ They helped provide emotional support and served as a strong communication liaison between the family and providers.

In addition, my research has shown that all families and young persons would benefit—separately and together—from more therapeutic support, ideally offered at home, in the evening, and possibly online. Therapy can help families rebuild trust and shared moral understandings—so important for moral agency—in the aftermath of a psychiatric crisis. Formal, clinic-based “interventions” provide information about ways to address practical issues, help families feel more supported, and increase the family’s confidence that they can support their relative.⁸⁰ Therapeutic “talking” interventions for families that also have been shown to help reduce relapse and hospital admission rates for people with psychosis and help improve social functioning.⁸¹ In addition, family interventions are thought to reduce the burden of care for families and better prepare them to provide care.⁸² Engaging family members may be especially important, as well, in working with persons from minoritized groups. In one review of mental health disparities among ethnoracially minoritized individuals with severe mental illness, identifying a family support person to include in doctor’s visits and providing family psychoeducation were both critical for lowering attrition.⁸³ However, I think most of the families I worked with would have loved having any of this work with families conducted in their home during a time when they were all present.

Probably the most comprehensive and best-researched family intervention is the Open Dialogue approach, which does typically occur in the home and often includes a psychiatrist, a psychologist, and a nurse.⁸⁴ This team follows the patient through inpatient and outpatient settings, from the first 24 hours after their possible initial first psychotic episode *for as long as treatment is necessary*. Having a secure team in place helps the young person and their family navigate the system. Team meetings are held at the patient’s home or another safe space and include at least two trained therapists, family members or another key supporter, and the young person. Hospitalization and medication are not the focus of treatment, are often delayed, and are used sparingly. Hospitalizations are not forced. Instead,

the foundation of the treatment is the Open Dialogue—an “equal” dialogue between the patient, the patient’s key supporters, and the therapists with a goal of increasing a sense of agency, motivating change, and creating a shared understanding of the situation. All participants discuss all issues openly and in the presence of all the other members of the team and family.

Research suggests that overall recovery rates using the Open Dialogue approach are often better than for people receiving treatment-as-usual, including a reduced need for psychiatric treatment and fewer psychotic symptoms.⁸⁵ A 19-year follow-up study in Finland that compared first-episode psychosis patients using the Open Dialogue approach to those using treatment-as-usual found that Open Dialogue users had significantly less overall need for hospitalization, antipsychotic medication, or disability allowances. For patients with more threatening behavior, however, the dialogical approach was less successful.⁸⁶ In addition, suicide rates were high in both Open Dialogue and control groups, indicating that psychotic experiences were still highly distressing, even with this more therapeutic and egalitarian, family-based approach.⁸⁷ Yet this treatment has helped many young persons and their families deal effectively with acute stressors and life crises.

In addition, encouraging everyone involved—the young person, their clinicians, and their key supporters—to voice their ideas and concerns in equal ways offered opportunities for new kinds of understanding while promoting shared decision making.⁸⁸ Much of what frustrated many of the young persons my team engaged with over time, which often led them to reject future mental health care, involved not feeling listened to by family and treatment staff throughout inpatient stays and beyond. This sense of dismissal may be softened by using an Open Dialogue approach that promotes mutual trust—an important part of the psychotherapeutic process.⁸⁹ In general, Open Dialogue users felt better listened to and understood than they did in other kinds of care experiences, though some patients with psychosis did find the meetings to be overwhelming and strange.⁹⁰

Unfortunately, it is not yet clear how well Open Dialogue translates to locations outside Finland. It has been offered in the United States in mental health agencies in Massachusetts, Georgia, New York, and Vermont. In Vermont, where it is called the Collaborative Network approach, one qualitative study found that it was well received, appreciated, and perceived as an empowering form of mental health care.⁹¹ A study in Massachusetts suggested that families liked having a space where they could process their experiences together, the involvement of the team in their lives, and the transparency of the Open Dialogue treatment process.⁹² Interviews with youths and family members in Vermont revealed that young people felt less singled-out when their families were included in the treatment process and that they felt they had learned as much from having their family present as their family and clinicians had learned from them.⁹³ An Atlanta-based team found that the approach was feasible and acceptable and had some positive effects even with less frequent meetings and without home visits.⁹⁴

However, more research is needed. In the meantime, some Open Dialogue principles might be adapted to offer families more therapeutic support at home or in a safe space after a psychiatric crisis.

STEP 5. MATERIAL SUPPORT

Research on state-of-the-art care for early psychosis suggests that it may work best for people with a high socioeconomic status.⁹⁵ It makes sense that low socioeconomic status would make it harder to find the material resources needed to access care. Thus, we must consider ways to offer more material support to young people in crisis and their families. It is not just the responsibility of individuals or clinicians or community supporters to promote youth mental health; it is the responsibility of us all, and some of that promotion is going to require ongoing investment in mental health care for those at higher risk who cannot afford to prioritize mental health care when they face so many other challenges.

One way we all can help is to agree to make mental health care cost-free for people who have experienced psychosis without requiring them to have a “disability” that renders them unable to work. Nearly everyone in my study reported having worked at some point prior to their first hospitalization. Evidence suggests that people who have psychotic symptoms want to work, but many ultimately seek out social security disability income or supplemental security income (depending on how long they have worked). Such assistance offers a living stipend to offset the financial burden of not being able to work and helps them secure mental health insurance through Medicare (after 24 months in the case of SSDI) or Medicaid (automatic for SSI) to help cover the high costs of medications and potential future hospitalizations.

Disability is expensive for the government to offer, though the details are hard to parse. Federal expenditures for SSI alone in calendar year 2022 totaled \$57.1 billion for 1.23 million individuals, of which about \$14.65 billion was allocated to persons with serious psychiatric disabilities such as schizophrenia and bipolar disorder.⁹⁶ Many people do need the monthly stipend to live on and many also need the Medicaid and Medicare to access and pay for mental health care.

Of course, this means that insurance is another area in need of reform. Mental health care is expensive, and accessing services early is difficult for families unless they have the right insurance. If they don't, accessing mental health care requires them to use emergency services, which is expensive, prevents early intervention, and can be a traumatic experience. At the hospital where I worked, the young persons who lacked insurance—presumably mental health insurance—seemed to be sent consistently for a long stay at the state hospital to meet Medicaid requirements, which was costly for youths and their families. The fiscal year 2024 “maximum daily rate of charge to individuals” for an inpatient stay in a Texas state psychiatric hospital was \$579 per day for “adults” and \$928 for “children and

adolescents,” which would add up quickly: 28 days for an adult would cost a person \$16,212.⁹⁷ This price is likely cheaper than a long stay at Shady Elms but is still staggering for most people I worked with to cover. No wonder Sage compared it to the costs of a year of college.

In 2014, when my fieldwork started, the Affordable Care Act had just made it possible for some of the young people to apply to stay on or reapply for their parent’s insurance until age 26. Insurers could no longer declare a history of psychosis as a preexisting condition and thus a barrier to insurance.⁹⁸ Some of these reforms have been helpful. Even so, among those who are in the early stages of psychosis and qualify for Medicaid based on income, the lack of a documented disability can preclude their access to Medicaid benefits that would cover early psychosis services, because the funding is limited to those with multiepisode schizophrenia and there must be at least one year of documented illness to apply. These requirements limit services that could help prevent people from becoming disabled in the first place.⁹⁹

Commercial health insurance and Medicaid programs also do not typically cover comprehensive early-psychosis services—and even when they do, what they cover is highly variable.¹⁰⁰ In one study, Medicaid covered around half of the costs of CSC, which excluded community outreach activities, team meetings, ongoing training, and supervision—all of which are needed to build effective programs.¹⁰¹ Both state and federal entities are actively investigating additional financing strategies and increasingly liaising with private as well as public insurers, but we need to continue to push these agencies to make changes that foster preventive and intensive early psychosis support for young persons before and after a crisis.¹⁰² One recent change (September 2023) for public insurance was to adopt a single code for billing for the package of CSC services at the federal level so that any CSC component, tailored to a person’s specific needs, could (in theory) be covered by a single code.¹⁰³ While the effects of the change remain to be seen, many consider this a step in the right direction for improving access to the full package of CSC interventions.

In one international review of primarily Western countries (one from China), 14 of 15 studies of early-psychosis intervention programs found that the availability of such intervention “resulted in reductions in total costs or were cost effective because they decreased high cost adverse outcomes,” such as by reducing the number of emergency room visits and high-cost inpatient hospitalizations, while improving a young person’s quality of life.¹⁰⁴ Despite the evidence, even if everyone had insurance, there are not enough early-psychosis programs available currently to meet demand. For example, in Texas each year about 3,000 young adults ages 12–25 are estimated to need early-psychosis services.¹⁰⁵ In 2014, when this study took place, there were only two CSC teams in Texas, and they were capable of serving 60 total young persons, representing 2 percent of state-level needs.¹⁰⁶ By 2016, when my study ended, there were only ten, with the capacity for 300 (10

percent of those in need). In 2022, around 1,366 clients were served in Texas by CSC teams,¹⁰⁷ which the Meadows Mental Health Policy Institute estimates as representing about 17.5 percent of persons needing those services in any given year. Nationally, it is estimated that more than 75,000 young persons go without access to CSC programs every year.¹⁰⁸

We can do better. This is not a money grab; it is a potentially self-sustaining investment in young persons' futures that may reduce costs drastically in the long run. CSC models cover two years and cost about \$15,000 per person per year—less than the 28-day inpatient state hospital bill many of the young persons we worked with likely received after their initial hospitalization. If we work instead to get people on track and avoid generating the need for crisis intervention, rehospitalization, and disability services, the savings for individuals, their families, taxpayers, and the government will be inestimable.

. . .

Opportunities to help young people prevent, approach gently, pass through, reorient to, and find treatment and support for experiences of psychosis through moral agency-enhancing practices are described throughout this book. This final chapter attempts to distill these into five steps we could take to radically transform care by strengthening its medical, material, and moral dimensions to help a young person protect their moral agency at a vulnerable time, which is key for moving forward into valued adulthood.

Moral agency is the catalyst for individual, familial, and societal belonging for any young person in the United States, including a person with early psychosis. Social belonging heals us all. We all need to be loved. The origin of the word *believe* is *beloved*.¹⁰⁹ We need others to see us as at least “good enough” for love—good enough to be beloved and believed—for our lives to have meaning.

If we pay attention to moral agency and offer young persons better support, many more can pass through their crisis and move forward with a life that is perhaps even more enriched and meaningful than it would have been otherwise. Not everyone who has experienced psychosis and moved on wants to share that story with others, so we do not hear about many of their stories, but I have talked to many people over the years who passed through this kind of experience, and more and more people are coming forward. Some of them have published research, first-person narratives, films, and artworks that have been crucial for me to understand psychosis myself, and I have no doubt there is much more to come as society embraces neurodiversity and understands that everyone has something to offer the collective whole. People with lived experience are doing their part to help, but all of us, as humans, can also become allies and do as much as we are able to help young persons experiencing symptoms of psychosis. Helping young people stay connected to people they care about and engaged in activities that are meaningful to them and reminding them that they are a “good enough,” beloved person

is crucial for them to envision a pathway to and through care. This care may be medical, it may be moral, and for many it will need to be material at times, as well, but if we commit to making sure that support is on offer and sometimes offer it ourselves, we can make a difference.

In this way, we can make psychosis a turning point—a moment when we realize a young person may need more accommodations to move forward, a moment when we commit to providing that support. This will require a societal turning point in the United States: the political will to make reforms, the social will to be allies for those of us with anomalous experiences, and the compassion to offer real financial support to improve youth mental health care and access to that care. When we exercise this will, we can turn some of these breaking points into turning points. And, in so doing, we can help a precious young person—full of incredible potential—to know that they are beloved and will find a life worth living.