

A STUDY GUIDE TO

*Fix What You Can:
Schizophrenia and a Lawmaker's
Fight for Her Son*

by Mindy Greiling

Prepared by Joshua E. Mervis

The goal of this study guide is to capture the complexity of mental illness from several points of view: those of parents, lawmakers, and persons living with a mental illness. By the end of this study guide you will better understand the daily, weekly, monthly, or more chronic events experienced by people with schizophrenia-spectrum illnesses (schizophrenia, schizoaffective disorder, and other syndromes with psychotic symptoms). *Fix What You Can* and the material in this guide show how complex it is to seek support from one's community and social circles. Some family members of those with mental illness find tremendous, eager support from their friends and family, but for many the picture is more nuanced and can be painful. Responses range from near condolences, as if a loved one's life were over; to warm sympathy with little knowledge but a willingness to learn; to significant and active support from those with lived experience of their own, in their family, or among their friends (and not uncommonly all three). The understanding you will develop in these pages will help you acquire empathy—bolstering your ability to support yourself and the people you care about—and will help you engage in mental health-related advocacy on small and large scales.

You are encouraged to reflect on how the book's concepts overlap with your own values. Through the combination of the main story, this guide, and introspective reflection, you will be able to (1) cultivate the inspiration to lead by example toward a world that is more compassionate; (2) develop the courage to reach out to those you know who might be struggling; (3) find the courage to reach out to others if you yourself are in need.

A Quick Word about the Words We Use

Illness, Disorder, Disease, or Syndrome: How What We Know Changes Our Perspective

In everyday life people often refer to the pain and suffering associated with the mind as some form of illness or disorder. There is no accepted convention on which words should be used, but we can look at the roots of the word psychiatry to explore how what we say matters. The word *psychiatry* comes from mid-1800s French *psychiatrie* and from Latin *psychiatria*, which seems to draw on the Greek word *psykhē* (more or less synonymous with the contemporary word *mind*) and the Greek word *iātreia* (healing or care). Together, they imply a healing of the soul. The word has roots in gentle language emphasizing care and healing. When reading through this study guide, take note of how the language changes and how that might or might not change your perspective.

What We Call a Mental Illness Matters

Throughout this study guide we use a number of terms to refer to the topic discussed in the book: (1) schizophrenia-spectrum illnesses or disorders, (2) first episodes of psychosis, and (3) psychotic disorders. The term *schizophrenia-spectrum illnesses or disorders* refers to schizophrenia, schizoaffective disorder, and other syndromes with psychotic symptoms. *First episodes of psychosis* represent a particular period early in the course of the disease, typically when an individual has had one major psychotic episode followed by some remission in

symptoms. *Psychotic disorders* is increasingly used as the overarching category for the other terms and is the clinical term used in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; the term will almost certainly change as new editions of the DSM are published; some people, especially in the broader European medical community, prefer the term *psychosis*). In the past, people with psychotic symptoms have been referred to with terms as diverse as *dementia praecox*, “a schizophrenic,” *schizophrenia-spectrum*, or *psychotic*. The terms we use frame the way we view the human context in which we actually live. People with psychotic symptoms are sons and daughters, mothers and fathers, friends and coworkers, mentors and healers, just like people without psychotic symptoms. The goal of any recovery-oriented intervention is to let an individual return to living a valued life as a person who happens to have psychotic symptoms.

How We Talk about People with Mental Illness Matters

Another point worth mentioning is that those who provide mental health treatment use a variety of terms to describe the consumers of mental health services. In this study guide, we use the words *client(s)*, *person (people)*, or *individual(s)* instead of the word *patient(s)*. We chose language that affirms agency for individuals with lived experience. We also chose this language to make it clear that these disorders or illnesses or whatever you decide to call them are happening in the context of a human being’s life. These considerations also apply to treatment environments and the words we use to describe them clinically. For example, the word *ward* has etymological roots in the idea of guardianship, which is certainly appropriate in acute settings when people are transiently a danger to themselves or others.

Exploring Themes in the Text

Find examples from the book where some of the topics listed here are mentioned. Discuss the topics as you cite these examples. Topics frequently overlap, so you may see references to the same topic in

more than one chapter. Bring your examples together to summarize the overall themes in each of these four areas.

Clinician Experiences and Engagement

Adjustment of the continuum of care when needed

Advocacy

Assistance in outpatient treatment

Collaboration with schools

Criminalization of mental illness

Diagnosis of mental illness

Harm reduction

Identification of early signs of mental illness

Identification of social and family support

Identification of vulnerable adult status

Management of medication side effects

Mental health court

Person-centered care

Placement on civil commitment

Prescription of medications across the life span

Consumer Experiences and Engagement

Advocacy

Anosognosia

Chemical dependency

Criminalization of mental illness

Delusions

Early experiences of mental illness

Effects on prescribed medications of using substances of abuse

Engagement with family members

Hallucinations
Harm reduction
Management of medication side effects
Mental health court
Participation in the continuum of care
Person-centered care
Stages of grief
Supported employment
Supported housing
Taking of medications
Victimization
Vulnerability status

Family Experiences and Engagement

Acquisition of medications
Advocacy
Caregiver burden
Criminalization of mental illness
Disability benefits
Early signs of mental illness
Guardianship
Harm reduction
Interaction with school climate
Mental health court
Parental involvement across the life span
Participation in the continuum of care
Stages of grief
Vulnerable adults

Social Environment Programs and Issues

Access to medications

Advocacy

Assisted outpatient treatment

Civil commitment

Confidentiality

Continuum of care

Criminalization of mental illness

Cultural and ethnic considerations

Deinstitutionalization

Disability benefits

Guardianship

Harm reduction

Hospital releases of information

Interaction with family and society

Mental health court

Parental involvement

Representative payee (an individual selected by the Social Security Administration to manage Social Security disability benefits in the best interests of the person who receives them)

School climate

Supported employment

Supported housing

Victimization

Vulnerable adults

Understanding the Major Specific Symptoms

Symptoms of schizophrenia-spectrum illnesses can be hard to understand for someone without lived experience. Even for the individual going through them, they can be confusing. Here are some descriptions of what people might experience as symptoms. As you review this list, you are encouraged to think about how these symptoms might affect you or a family member. In what way might your lives be different? In what way might your lives be the same? None of these examples is exhaustive, covering the full, wide range of what these experiences can look or be like. It is also important to note that these are primary symptoms of schizophrenia, but a person may also experience symptoms of social anxiety, depression, or substance use.

Delusions

A delusion is a belief about the world that is not verifiable by others who have the same information about the environment. These beliefs can be subtle—a person might wonder if something is true but not believe it. But a delusion can also be complete and total belief in an idea. For example, someone might believe he or she is a figure from history (such as Joan of Arc). Romantic delusions are also possible: people believe they are in a relationship with someone they know or someone famous. Other delusions may create suspicion: people may feel that others are talking about them or that the government is following them. Delusional thoughts can seem strange or bizarre to others and to the individual.

Hallucinations

A hallucination is a sensory experience that cannot be verified by others. Hallucinations can be distressing, neutral, or even pleasant, and they can change over time. The most common type of hallucination for people with schizophrenia is hearing something that others do not. What is heard can be anything from breaking glass to a marching band, but most often it is voices that comment on the person's behavior or tell him or her to do or not do things. Under a hallucination,

it is also possible to see things that others do not see; for example, a person may see people others cannot. Some people have hallucinations that involve taste, smell, or sensations on their skin—for example, a person might feel strange, perhaps painful sensations in the head (but these are less common).

Disorganized Speech

Disorganized speech is hard to describe. It can be portrayed as a loss of grammar, as if the speaker is stringing together random words—so-called word salad. Researchers think this disorganization is a behavioral manifestation of cognitive dysfunction that comes about through brain changes or differences. Disorganized speech is easier to understand if you hear it, so you are encouraged to seek online for videos illustrating it.

Grossly Disorganized or Catatonic Behavior

A person showing grossly disorganized behavior may be undertaking an activity in a strange way or moving in a way that is not typical for most people. A person showing catatonic behavior may be standing as still as a statue or moving lethargically, without energy. Catatonia is not unique to schizophrenia-spectrum illnesses; it can occur in a variety of other medical conditions.

Negative Symptoms (Such as Diminished Emotional Expression)

Negative symptoms look a lot like depression. People have a hard time mustering the motivation to start and continue activities. Sometimes people do not speak much; sometimes they experience thought-blocking episodes in which they cannot think. Scientists used to believe that people with schizophrenia sometimes could not feel pleasure at all, but more-current research suggests that people with schizophrenia have difficulty expressing pleasure.

Understanding Common Nonspecific Symptoms

It is important to note that the symptoms leading to a diagnosis of a schizophrenia-spectrum disorder may be only some of the symptoms a person experiences. Individuals with schizophrenia-spectrum disorders can also experience depression or withdrawal from social situations, or they may have a hard time reading the emotions of other people. In many cases, people might experience substantial changes in sleeping or eating patterns and in their ability to take care of themselves and complete tasks of daily living. Other common symptoms are cognitive distortions (such as the belief, without evidence, that a person will fail at whatever he or she tries to do) and cognitive dysfunctions (such as having trouble focusing or exerting mental effort).

In depression, people feel down, sad, or anxious and sometimes experience periods of tearfulness. They may waffle over choices, experiences, or minor decisions. These symptoms range from mild to severe and are usually worse during periods with more intense hallucinations or delusions. Depression is common in chronic mental and medical illnesses. A person experiencing changes in social behavior might withdraw from friends or family, particularly during increased levels of other symptoms such as auditory hallucinations and, especially, auditory commands. People might also experience alterations in how they interpret the emotions of others, including fear, sadness, and joy. Many observers will notice changes in the emotional relationships a person with a schizophrenia-spectrum disorder has with their peers and friends. Changes in sleep patterns can precede increases in symptoms or full psychotic episodes. Changes in patterns of self-care might show up as difficulty in cooking for oneself, maintaining physical hygiene, managing money, or navigating public transit. Cognitive disorganization can result in changes in school or work performance and can range from mild concentration issues to substantial inability to follow a conversation.

Before people fully develop schizophrenia-spectrum disorders, they may experience symptoms that do not yet warrant a diagnosis (subsyndromal experiences). These symptoms include generalized

or social anxiety, persistent depressed mood, and reduced drive, energy, and concentration. As mentioned above, sleep disturbances are common. Behavioral changes such as deterioration in the ability to perform as expected in school or at work can delay educational or vocational achievement, including graduating or getting a new job. In more advanced subsyndromal symptoms, a person may experience attenuated psychotic symptoms, usually as mild to moderate perceptual abnormalities, such as seeing things that are not there or feeling suspicious of others. Individuals experiencing substantial amounts of these symptoms might receive treatment, including psychopharmacologic and psychosocial interventions, even though they do not yet meet the criteria for schizophrenia-spectrum disorders.

Questions by Major Theme

1. One theme that occurs throughout this book is the experience of the family as well as of the individual with lived experience of mental illness. How might events like those in the book affect your family, and what challenges or strengths do you see in your family?
2. Another theme is the emphasis on a recovery process and how that looks across the life span. What recovery-oriented goals would you find useful if you had or have lived experience? What might you find useful if you were Jim's therapist or case manager?
3. Advocacy is a theme of this book. How could you best advocate for a family member at the policy and treatment levels? Is advocacy more necessary in the mental health system than in other areas of health care? Why or why not?

Questions by Chapter

Many topics overlap throughout the chapters. Use online resources and other relevant readings as you think about these questions.

1. The Call

- a. What does the process of diagnosing schizophrenia look like?
- b. How could early-detection clinics strengthen community mental health through outreach programs?
- c. What is the role of medication in staying well after a first psychotic episode?
- d. What is the intention behind civil commitment?
- e. How might people currently experiencing significant symptoms of schizophrenia view an effort to secure their commitment?
- f. What are the ethical considerations related to involuntary treatment, such as commitment?
- g. What are the challenges in diagnosing and treating people who do not believe they have a mental illness?
- h. How can individuals and families improve the likelihood of success in returning to school or work? How might they manage the accommodations that need to be made to successfully return?
- i. Why might individuals who are experiencing their first episode of psychosis end up in jail or under arrest for committing crimes?
- j. What do we know about the effects of marijuana, hallucinogens, or other substances on the onset and course of schizophrenia? How might using such substances constitute self-medication?
- k. How might symptoms like irregular or inappropriate emotional responses (emotional dysregulation), declining school or work performance, and isolation from friends look as early symptoms of schizophrenia?
- l. What ethical and practical considerations do attorneys face in

helping individuals with schizophrenia-spectrum disorders navigate the criminal justice system?

- m. What ethical and practical considerations do mental health professionals face in helping individuals with schizophrenia-spectrum disorders navigate the health care system?
- n. How might the diagnosis of a first psychotic episode affect parents, siblings, partners, and friends?
- o. How might the diagnosis of schizophrenia begin a grieving process? What might that grieving process look like in the individual receiving the diagnosis? In a family member?

2. Alarm Bells

- a. What early signs might have appeared in someone who later developed a schizophrenia-spectrum disorder? What does current research say?
- b. How might a change in hygiene indicate functional impairment? What about a change in financial management?
- c. What does social anxiety look like in people with schizophrenia?
- d. What is the effect of teenage substance use on the risk for developing schizophrenia? What does current research say?
- e. What does Jim's experience of feeling like something was wrong from the time he was eleven suggest about the disease course?
- f. How might parents or caregivers experience guilt surrounding illness? Could they have done anything either to prevent or to cause the illness? What is the current state of research on self-stigma and guilt in families of individuals with any chronic illness?
- g. What might make caregivers hesitant to accept the diagnosis?
- h. What role does hearing voices play in schizophrenia?
- i. How are the family members of a person who has some of the symptoms of schizophrenia affected?

- j. What does current research say about the heritability of schizophrenia-spectrum disorders?

3. Bum

- a. How might family members react to symptoms? How might fluctuations in symptoms play into a family's acceptance of a diagnosis?
- b. It is important to treat substance use in people with schizophrenia-spectrum illnesses. How might these substances interfere with medications for psychosis?
- c. Which professional standards and ethics in clinical practice mandate that providers warn or report potential injury to the client or someone else?
- d. When might it make sense for a provider to break confidentiality with a client?
- e. What are the pros and cons of using language about disease severity? What are the implications of describing a mental illness as "severe" or "serious" and "persistent" or "chronic"?
- f. What daily challenges might be experienced by someone who is paranoid or who has delusions? What impact might these symptoms have on their social relationships?
- g. How might access to psychiatrists, psychiatric nurse practitioners, or primary care doctors affect the disease course?
- h. What roles might socioeconomic status play in the disease course?
- i. Why might parents feel a need to "defend their genes" when their child develops psychosis or related disorders?
- j. At the University of Wisconsin-Madison in the 1960s, famed psychologist Harry Harlow studied parenting in rhesus monkeys by using various types of surrogate mothers (for example, wire or cloth surrogates) or isolation without a surrogate. His studies found that malfunctioning in rhesus monkeys could be

associated with mothers' parenting styles. How might studies like this lead to internalized stigma in parents of children with schizophrenia-spectrum disorders?

- k. Identical twins share 100 percent of their genes. However, when one identical twin has schizophrenia, the other twin has a nearly 50/50 chance of developing the illness. What might the role of trauma or other environmental stressors (including early substance use) tell us about how social factors play into illness development?
- l. If you were going to design a program to treat first episodes of psychosis, what kinds of support would you include?

4. Psych Ward Silence

- a. What are some of the feelings parents or caregivers might experience when having to call 911 or send their child to a shelter as the fastest way into treatment in the mental health system?
- b. Why do we have legal guidelines for mental health crises that limit police involvement to cases where individuals are a danger to themselves (more likely) or to others (less likely)?
- c. What is the strategy behind crisis teams? How might crisis-specific outreach teams support community treatment?
- d. Crisis teams staffed by emergency medical technicians often have special training and will turn off an ambulance siren as they close in on a location. How might this help prevent a challenging situation from escalating?
- e. How might a person with schizophrenia react to being transported from one place to another by a local sheriff? How might delusions or paranoia symptoms interact with the situation?
- f. Why might family members need to get release-of-information permission from a child before a hospital can coordinate care with them? How would this be different for a minor versus an adult? How might this be even more challenging across state lines?

- g. Why do family advocacy groups and mental health groups that represent people who have mental illnesses sometimes view releases of information differently?

5. Sharing the News

- a. How can parents best explain a child's diagnosis to siblings? How could support from the full family be beneficial?
- b. What medications and services are available now that were not available to Grandma Teddy? What about your own grandmother's generation?
- c. With deinstitutionalization, Grandma Teddy tried to live in an apartment with little assistance. What are the considerations for independent living for people with psychosis?
- d. Do people have a single episode of psychosis and never have another one?

6. Frustration Inspires Legislation

- a. How common are incidents of violence involving people with a severe mental illness? What does current research say? How is this consistent or inconsistent with media portrayals?
- b. What safety measures are in place to prevent a person being discharged from the hospital before being stable? Would family involvement be helpful, if available?
- c. What might be important considerations for chemical dependency facilities' ability to treat people who also have a mental illness?
- d. How are hospitals' release-of-information policies implemented differently for physical and mental illnesses?
- e. What are the roles of school systems and higher education facilities in mental illness?
- f. Why might lawmakers support policies allowing civil commitment

options? How might these policies address the related issue of individual rights?

7. Allies in Empathy and Action

- a. What is the importance of earlier care for people who are psychotic?
- b. Eileen Stack's son killed his father during a psychotic episode. How often do persons with schizophrenia-spectrum disorders physically harm others?
- c. How can families help their loved ones get the earliest care possible?
- d. What are the pros and cons of allowing incarcerated people to refuse medication unless they meet civil commitment standards?

8. Angela Visits

- a. In 1999, Anoka-Metro Regional Treatment Center was commonly used for longer-term care after inpatient psychiatric stays. Today it is mostly filled with people sent from jails because of changes in state laws. What challenges does this pose to the level of care provided?
- b. How can longer stays in secure facilities be useful for overseeing the selection and titration of medications?
- c. Not everyone fully responds to antipsychotics, and contemporary guidelines for psychopharmacology suggest using more-effective medications that have more-dangerous side effects after first-line treatments fail or do not provide satisfactory improvement. How might the management of such side effects create an additional burden for caregivers?
- d. What are the pros and cons of using smoking as a reward for people participating in treatment while in an inpatient unit?

- e. Contemporary research in smoking cessation suggests that it is easier to stop smoking gradually than abruptly and that a majority of people with schizophrenia-spectrum disorders smoke or have smoked cigarettes at one point. How might using smoking as a reward for inpatient, outpatient, or family management not be helpful to treatment goals?
- f. Why might social anxiety be a major target of treatment in long-term psychosocial rehabilitation from schizophrenia or psychosis?
- g. How can schools support people with schizophrenia as they support other students who need accommodations?

9. Advice from a Prisoner

- a. Is schizophrenia a lifelong illness?
- b. Sometimes people with mental illness will decide to stop taking their medication after their symptoms are stable because they think they're cured. What are the current statistics on how well people with schizophrenia-spectrum disorders stick to their medication regimen?
- c. What might lead a person to later appreciate having been assessed and treated involuntarily?
- d. Is there any research on the rates of involuntary hospitalizations in mental illness overall? What about for schizophrenia-spectrum disorders in particular?
- e. How is the issue of consent different in treating mental illness and other illnesses? What are some ways professionals can support consumer-driven care?
- f. For mental illnesses on the schizophrenia and bipolar illness spectrums, psychiatric medications sometimes do not work as well, or do not work at all, if a person has stopped taking them and then wants to restart. How might this create long-term barriers to treatment in people with chronic mental illness?

- g. What does current research say about possible diminishing returns on medications when people stop taking them?
- h. People with mental illness are overrepresented in jails and prisons, greatly contributing to their stress. What barriers to treatment exist in jails and prisons and how might they be overcome?
- i. What are the current statistics on the number of incarcerated people who have a mental illness or a serious mental illness?
- j. Some former mental hospitals, such as the Rochester State Hospital, have since been converted to prisons. What might that say both about the prior treatment of those who were mentally ill and about contemporary perspectives on incarceration? How many current prisons used to be psychiatric hospitals?
- k. What is anosognosia? What does it mean at a social level if your inability to know that you have an illness is a symptom of the illness?
- l. How might substance use induce psychosis or episodes of mania? What does current research say about this?

10. The Third Rail

- a. How might individual-rights advocacy groups view civil commitment? How about groups that focus on families of people with lived experience?
- b. What does it mean to be a treatment advocate? What is the role of groups like the Treatment Advocacy Center?
- c. The Minnesota Mental Health Legislative Network is an umbrella group of about forty mental health groups. The National Alliance on Mental Illness (NAMI) and Mental Health Minnesota share the leadership. What would be a challenge in working within an umbrella group for advocacy?
- d. How can we use modern strategies to provide mental health resources to students? What are some contemporary approaches in your community?

11. One of Them

- a. What could be done to ensure the fair treatment of people with mental illness in the legal system, including jails? How can families support this?
- b. How does biased treatment of people with mental illness reflect the criminalization of psychopathology?

12. Early Intervention

- a. What are some advantages of working with legislators and advocacy groups to change mental health policies? Are there any current policies you believe need changing?
- b. Legislators seem to find family stories of mental illness useful in shaping policy. How can legislators effectively engage families?

13. Tasks Unlimited

- a. What ethical dilemmas are raised by families having to refuse to care for their family members in order for them to receive benefits?
- b. What is the role of supported employment in recovery?
- c. What are some of the potential challenges with employment when management is aware of mental illness–related disability?
- d. What are some challenges related to weight gain from anti-psychotic medications?

14. Debating the Governor

- a. What needs to be considered in deciding how early we could offer antipsychotic medication to people with schizophrenia-spectrum illnesses?
- b. What are the current guidelines for prescribing medication for early-stage intervention for people with schizophrenia-spectrum illnesses?

- c. How can we best explain to families the risks and benefits of early antipsychotic medication use?
- d. Is there any connection between a person's taking psychiatric medications and his or her likelihood of committing crimes?
- e. What issues are raised by media depictions of all mass shooting perpetrators as mentally ill?
- f. What is the actual rate of violent crimes committed by people with mental health issues? At what rate are people with mental health issues the victims of crimes?

15. "This Bill Will Save Lives"

- a. How can advocacy initiatives define or support an active role in caregiving throughout the disease course?
- b. How could participating in advocacy work give families a sense of agency?

16. Mind over Fat

- a. Weight gain is a serious side effect of many effective antipsychotic medications. What treatment strategies might help manage this side effect?
- b. People on antipsychotic medications often face additional medical problems that are brought on by their psychopharmacological treatment and that require careful monitoring. This is one of the biggest reasons why most individuals taking these medications see a psychiatrist or psychiatric nurse practitioner every four to six weeks or so. Issues include, but are not limited to, obesity, cardiovascular disease, diabetes, high blood pressure, or hyperlipidemia. They can be caused either by medication-induced weight gain or by metabolic syndromes, and their coexistence makes each worse. What factors might go into a risk/benefit consideration for these individuals?

- c. What does current research say about the general side effects common to most antipsychotic medications?
- d. How can medication-induced sedation be balanced with a person's need to actively engage with a job or the community?
- e. Agranulocytosis is a dangerous side effect of clozapine. Why do providers use medications with life-threatening side effects? Why is it important that prescribers be comprehensively trained in medicine?
- f. How might medical insurance dictate the course of the treatment an individual receives?

17. Jim Is Amazing

- a. How can hospital policies on releasing information create complications when individuals are not able to sign releases because of their condition?
- b. How might local communities create programming to support increased care for people with schizophrenia?
- c. How might insight into illness be helpful for treatment planning and at the same time be challenging in a psychotherapy context?
- d. What percentage of people with schizophrenia-spectrum disorders have insight into their illness, according to current research?

18. The Depths of Delusion

- a. Delusions are challenging for clinicians to address. What might make delusions particularly difficult to work with? How might you go about talking with someone about those beliefs?
- b. Schizoaffective disorder includes symptoms related to schizophrenia and to either bipolar disorder or major depressive disorder. What might be a challenge in treating an illness with complex symptoms that might require different medications?

- c. Tardive dyskinesia is a scary side effect of many antipsychotic medications. It can be permanent and includes uncontrollable movements in parts of the body. People who experience these symptoms might first notice that their tongue seems to wiggle a bit in their mouth. How common is tardive dyskinesia?
- d. How might client self-monitoring for symptoms help mitigate problems from side effects as soon as possible?
- e. What is currently known about the impact of cannabis use on psychiatric symptoms in general? What about in schizophrenia-spectrum disorders?
- f. How do programs like Social Security Disability Insurance or Medicaid/Medical Assistance create an important safety net for people with chronic mental illness?
- g. How many people with schizophrenia-spectrum disorders receive some form of government benefits?

19. Vulnerable Adult

- a. Antipsychotic medications cause weight gain in part as a secondary side effect: they make people feel hungry. What behavioral strategies might help manage this?
- b. Since individuals with schizophrenia-spectrum illnesses might have a fluctuating ability to make financial decisions or to advocate for themselves, they can be taken advantage of. What kinds of laws or protections might work to prevent this?
- c. How might a problem in communicating with or understanding others create a challenge in social functioning?
- d. How can families manage persistent, long-term grief over the life they had expected for family members with a mental illness?
- e. What is the role of family therapy in the contemporary treatment of schizophrenia-spectrum disorders?

20. Mother's Day Turmoil

- a. What is the philosophy underlying the use of peer helpers and related programs? How can family advocates, often individuals whose child or sibling has lived experience, provide an important support for families? What might make this support particularly important during the early-diagnosis phase?
- b. Hospital admission standards can be different from civil commitment standards. A person who meets civil commitment standards may still not be eligible for hospital admission. How can the disparity between the two create a problem in acute care?
- c. How can chemical dependency and the need for related treatment complicate the treatment of chronic mental illnesses like schizophrenia-spectrum disorders?
- d. Chemical dependency is not uncommon in schizophrenia-spectrum disorders. How might families use relapse-prevention plans or reengagement plans to support a loved one?
- e. How might being a parent of an adult who needs care past a developmentally typical age change one's views on parenting across the life span?

21. Really Bad News

- a. Mental health-related legislation is often inspired by a constituent family's story and situation. How might families take advantage of this to advance additional policies that serve people with mental illness?
- b. Treatment-oriented mental health courts sometimes handle cases for individuals with substance use problems in addition to mental health conditions. The idea behind this model is to mandate mental health services and possibly to reduce or eliminate criminal records in order to set up the opportunity for recovery. How can mental health courts serve as an option for reducing the severity of crimes committed under the influence of psychiatric symptoms?

22. ACT

- a. How can public programming create opportunities for stability and community engagement in people with mental illnesses like schizophrenia? In what domains of life might a person need additional support?
- b. What is Assertive Community Treatment (ACT)?
- c. How can ACT teams best assist clients in gaining access to needed programs?

23. Celebrating in Mental Health Court

- a. What are the major ethical dilemmas in legal issues related to mental illness?
- b. How is mental health court different from criminal court? Why is it seen as a better option than criminal court for persons with mental illness?

24. The Risk of Hospitality

- a. How prevalent is the victimization of people with mental illness? What can be done about it, given their right to independence?
- b. What role can psychologists play in preventing victimization? Should parents communicate with psychologists about this?
- c. A Minnesota law now makes parental involvement in ACT teams possible. What might parental involvement contribute to the clinical care team?

25. Colleen

- a. Substance use is common among people with chronic mental illness. What might motivate increased substance use in people with mental health issues?
- b. The changes that can occur in short- and long-term goals after the onset of schizophrenia can create difficult comparisons. For

example, a person with schizophrenia may not experience the life milestones that his or her siblings do. What challenges would this create in the family dynamic?

- c. How can people with mental illness who are vulnerable to manipulation be taken advantage of financially or in other functionally impactful ways?
- d. How can parents work to set up money-management systems for their children who are coping with a chronic mental illness?

26. A Better Job

- a. How might having any kind of job be important to the development and maintenance of self-esteem? How might employment be particularly important in psychosocial rehabilitation from mental illness?
- b. How can parents prepare themselves to be lifelong mental health advocates for their children?
- c. What challenges might supported employment or related transitional work environments create for people with mental illness?
- d. Where is the line between workplace accommodations for mental illness and accountability? How can that line be ethically managed?
- e. How might the co-occurrence of developmental disability and schizophrenia create additional treatment challenges? How might these challenges change your ideas about how to effectively engage such a person in a family setting?
- f. Peer specialists are an important part of the treatment milieu in that they provide information and support from a person with lived experience of a particular condition—in this case, a mental illness like schizophrenia. What might make a person an effective peer specialist?

27. One Very Lucky Young Man

- a. Some social workers are case managers, others are therapists, and some are both. What might the day-to-day role of a social worker who works with mental illnesses such as schizophrenia look like?
- b. People with mental illness might stick with unhealthy relationships longer than people without it, especially if they have small social circles or struggle to meet people. Given that social functioning can fluctuate in people with schizophrenia, what might be the characteristics of supportive friends?
- c. What challenges in a family's involvement in care might create rifts among family members?
- d. When divorce is related to the burdens of illness or to disagreements on treatment, how could a family manage the need to coordinate care? What about if siblings disagree with their parents' decisions?
- e. Some medications cause side effects such as swollen breasts in males. How might that kind of side effect influence a person's adherence to a prescribed medication regimen?
- f. What should be the threshold for the guardianship of another person? What degree of functioning must someone be below to have a guardian?
- g. How can the need to stop medication regimens for surgery create complexities in recovery? How might providers manage this?

28. Care-Meeting Chaos

- a. How can hospitals communicate effectively and compassionately with people who have a mental illness, their family, and other caregivers?
- b. Smoking is relatively common among people with schizophrenia. How might smoking complicate existing medication side effects and create additional risk factors?

- c. Advance directives define the parameters of the care people receive when they're unable to make decisions. Individuals with schizophrenia might benefit from advance directives so as to be active in their own care. Additionally, such directives could make it easier to manage the release of information. What kinds of provisions might make sense in an advance directive for someone with a mental illness?
- d. Coordinated care allows an interdisciplinary team to weigh in on assessment and treatment. What might be the benefit of shifting some treatment planning away from psychiatrists alone?
- e. How might social and legal policy best address situations when individuals with mental illness commit crimes while sick?
- f. Substances like cannabis or hallucinogens and other psychedelic drugs exacerbate symptoms in people with schizophrenia and perhaps in some other chronic mental illnesses as well. How can treatment providers work with patients to develop harm-reduction approaches?

29. Deny, Enable, Repeat

- a. How can instability in a person's primary environment create issues with social and job functioning?
- b. How might things like credit ratings and background checks create barriers to recovery by preventing access to intermediary levels of publicly funded care?
- c. How might groups like Alcoholics Anonymous and other twelve-step-style programs create a sense of community to support recovery?
- d. What might be some of the psychological mechanisms underlying divorce of couples who are supporting children or family members with mental illness?

30. Jail instead of the Caucus

- a. How can jails, prisons, and other components of the legal system support the care and the rights of vulnerable adults?

31. Escape to Puerto Vallarta

- a. How can different hospital admission standards for mental illness versus chemical dependency create conflicting situations?
- b. Amid all the seriousness of managing schizophrenia-spectrum illnesses, there might be moments of levity and laughter. How might laughter and engagement with others benefit people with chronic mental illness and their families?

32. Relapse and Roses

- a. Family psychoeducation programs can focus on a variety of topics from disease characteristics to treatment planning. How might family psychoeducation address the dual diagnosis of schizophrenia and related chemical dependency?
- b. How might having several relapses create challenges in interacting with the legal system in general and with civil commitment in particular?

33. Treat to Street

- a. The term *treat to street* refers to hospitals' practice of treating people and then releasing them without a plan for their continued care. Is anybody responsible for ensuring this does not happen to people who are very ill with mental illness?
- b. Drugs like methadone provide an alternative to help control addiction to other, more dangerous opiates, but there is no similar substance yet for crack cocaine. What kinds of future research might play a role in fixing this disparity?
- c. How might an intensive residential treatment service (IRTS) that allows substance use under the harm-reduction principle,

even when civil commitment orders forbid them to, promote a recovery-oriented approach to care? Harm reduction can include abstinence from substances; does this work?

34. Where Will Jim Live?

- a. Access to affordable housing is useful in the long-term support of people with chronic illness. However, landlords might be particularly wary of someone with a background that includes mental illness and legal trouble. How might this limit options for people with mental illness?
- b. Substances of abuse appear to negatively affect the brain and to do so progressively over time. How might time away from using them allow the brain to heal?

35. Hope in the Shadows

- a. The role of colleges and universities in the early identification of schizophrenia-spectrum illnesses is critical. What kinds of outreach might make the most sense for these communities?
- b. How can providers promote an active role for parents and family members in supporting a person with mental illness?

36. Home, for Now

- a. Community Access for Disability Inclusion (CADI) waivers and related programs provide major community support for people with schizophrenia-spectrum illnesses, yet navigating the system is a special skill. What issues might be related to the ease or difficulty of gaining access to public services?

Epilogue

- a. In the past, mental health hospitals had more flexibility in making sure that people took medications on inpatient units and in communicating with family members about treatment. How might changes in technology and concerns about privacy, which

led to health care laws on sharing information, serve as strong protection on the one hand or unintentionally impede treatment on the other?

- b. What might be better about today's mental health system compared to that of the 1950s?
- c. What are some common factors that have caused the same number of people to be in jails and prisons today as were in mental hospitals in the past? What are the new factors?
- d. How can chemical dependency leading to crimes committed to get money for drugs complicate functional recovery?
- e. People with schizophrenia-spectrum illnesses are at higher risk for suicide. How can families and friends help by broaching what often feels like a taboo subject?
- f. Research shows that parental involvement supports recovery. Why, then, do so many parents complain about not being included?
- g. How can treatment centers best engage families coming from minority backgrounds or lower socioeconomic groups?
- h. Schizophrenia-spectrum illnesses have biological underpinnings, reflecting the importance of viewing these illnesses as brain diseases. What is the goal of research seeking to understand the neurobiological elements of schizophrenia?
- i. The duration of untreated schizophrenia-spectrum illnesses has an impact on their long-term trajectory. How can communities support early intervention?
- j. Why does an ambiguous loss—for example, mental illness, traumatic brain injury, or Alzheimer's disease—often feel more difficult to deal with than death?

Resources

The literature on schizophrenia-spectrum illness and mental illness more broadly is vast and changes frequently to reflect new research. You may find useful information and support resources through the websites of the following organizations.

American Psychiatric Association www.psych.org

Brain and Behavior Research Foundation www.bbrfoundation.org

Mental Health America (MHA) www.mhanational.org

Mental Health Minnesota www.mentalhealthmn.org

Minnesota Psychiatric Society www.mnpsychsoc.org

National Alliance on Mental Illness (NAMI) www.nami.org

National Alliance on Mental Illness Minnesota (NAMI-MN)
www.namimn.org

National Institute of Mental Health (NIMH) www.nimh.nih.gov

Treatment Advocacy Center www.treatmentadvocacycenter.org