

# BEDLAM

AN INTIMATE  
JOURNEY INTO  
AMERICA'S  
MENTAL HEALTH  
CRISIS

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DISCUSSION GUIDE



## SECTIONS COVERED

### Author's Note

### Prologue

### Chapter 1: How It All Began

1

Why did you choose to pick up this book? What were you hoping to learn or demystify about the topic?

2

"Rather than a project *about* a glimpse of patients and doctors in the ED [emergency department] over a few hours, the project became a close and ongoing collaboration *with* the doctors, patients, and families to tell their stories as they evolved over the course of time." (ix)

Does this embedded approach give the narrative more weight or authenticity? Did you feel this exploration of mental illness was more well rounded than other studies?

3

"My family's tragedy is an American tragedy. My family's shame is America's great secret. In this country, one in five adults (and one in five families) lives with a mental illness, according to the National Institute of Mental Health." (xiii)

Do you consider this ratio high, or higher than you thought it would be? Do you have a personal relationship or familial relationship to mental illness? Does this statistic resonate with you?

4

The author clarifies the difference between the medical terms for those with serious mental illness (SMI) versus the "so-called worried well." (xiii) What differentiates these groups? Why would there be cloudiness in diagnosis for someone suffering from disabling panic attacks or PTSD? Why are there gray lines?

5

"Stigma causes people to feel ashamed for something that *is* out of their control. . . . Worst of all, stigma prevents people from seeking the help they need." (xv)

How does this book break down the various forms stigma can take? Have you encountered such stigma around mental illness—and how did you react to or internalize it?

6

Have you ever sought treatment or self-diagnosed for mental illness, or witnessed someone close to you do so? How did your experience compare with the author's of witnessing his family's evolving relationship to Merle's disease?

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## Author's Note

### Prologue

#### Chapter 1: How It All Began

- 7 "To my working-class Jewish parents, any mental illness was a *shanda*, Yiddish for 'disgrace.'" (4) How can culture, faith, or tradition inform or deny the stigmas we carry around?
- 8 Why is the word "bedlam" so powerful? "A word now synonymous with disorder and mayhem, Bedlam was the colloquial name of England's Bethlem Hospital, which was founded as a priory in 1247 and has cared for 'lunatics' from 1377 to the present day." (4) Did learning the term's historical roots, and how the site was used as a tourism spot, shock you? Was mental illness a death sentence in those times?
- 9 How have movies or other forms of entertainment explored what it is like to be a person with mental illness or one who cares for a person with mental illness? Can you think of examples of those incarnations where the experience was portrayed "right"?
- 10 Did learning about the "great and desperate cures" (22)—focal infection therapy, insulin comas, electroconvulsive therapy, and leucotomy (frontal lobotomy)—give you more insight or understanding into how we got to this tender place in psychiatric care? Was it a challenge to read this medical history and about these forms of care?
- 11 From President Kennedy to each of the major thought leaders and doctors featured in this book, how is the personal political or the personal professional? How does having a backstory with or a personal connection to mental illness seem to feed the scholarship and urgency of the research?
- 12 "Today, roughly fifteen thousand people struggling with serious mental illness live on the streets in Los Angeles, and the Los Angeles County Jail is the largest mental treatment facility in the nation. For many patients needing psychiatric care in the area, the last refuge is the busiest emergency room in America at LAC+USC Medical Center." (29)  
Why is LA's skid row ground zero for, or a perfect example of, how the mental health crisis is ravaging our communities? In what ways are our law enforcement structures ill suited for the needs of our sickest citizens?

## SECTIONS COVERED

### Chapter 2: Me-Too Medicines

1

What is a “me-too” drug? “A number of very large drug companies have withdrawn from looking for new treatments for psychotic illness, which is very, very consequential for the field.” (44) In what ways is this problematic for our quest to unpack the secrets of the brain, its chemistry, and its firing? How is the lack of innovation and investment a burden for providers and patients?

2

“Make no mistake about it. On balance, these medicines save lives and are essential for most people to get better. But they are also undoubtedly problematic.” (38)

What are some of the trickiest side effects patients endure while on these strong meds like Seroquel or clozapine? What are the trade-offs patients make?

3

Discuss Johanna's struggles in this chapter (“If I can't make it, what about everyone else?” 53): coming from a place of seeming privilege, but suffering dependency and desperation. Is her persistence her secret weapon?

## SECTIONS COVERED

### Chapter 3: Dungeons and Dragons: Criminalizing Mental Illness

### Chapter 4: Throwaway People

1

“‘In England, they've largely not used restraints for over two hundred years. We should be able to do the same things.’ Others see restraints as a necessary evil—the only way to ensure patient and staff safety in a dangerous situation—especially in today's EDs [emergency departments] when patients may be intoxicated, they may carry weapons, or their psychosis may make them combative.” (75)

Given all this context, do you agree that restraints, which may traumatize patients, are a necessary evil? Or is the practice cruel? Should there be a more “Goldilocks” approach?

2

Before reading this book, did you harbor theories about what causes mental illness? Or did you assume there was “an interplay of influences in every case, not just a single trigger” (76), as the author presents? How do nature and nurture, poverty and trauma, and substance abuse contribute to illness?

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## Chapter 3: Dungeons and Dragons: Criminalizing Mental Illness

### Chapter 4: Throwaway People

3

"If you're poor, if you're crazy, they want to keep you down, or lock you up. I mean, how many years have I been with Mental Health? Forty-three years and they still haven't fixed me." (86)

Discuss Todd's background and his perspective on his care. In what ways have social services intervened, and what aspects of his life and needs (food, shelter, medical care) must he patch together himself? Why might that be a challenge for someone in his position? How does it become a cycle?

4

What reasons might someone with a serious mental illness turn to self-medicating with street drugs? How might they be trying to treat their symptoms?

5

"Meanwhile, she says, only 5 percent of psychologists in this country are African American (there are even fewer African American psychiatrists). As a consequence, black people are more likely to get care from nonblack providers, which can lead to miscommunication, inaccurate diagnoses, and subpar care." (58)

Why are these findings extremely troubling and problematic? What ramifications can you immediately see from these statistics?

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### Chapter 5: "My Son Died with His Civil Liberties Intact"

1

What are the differences between therapeutic jurisprudence, assisted outpatient treatment (AOT), and conservatorships? In what ways can they be the most ideal option for guiding a patient into effective treatment programs? How could they be beneficial to families, especially in the author's family's situation? (92)

2

"Advocates say the programs save lives, reducing crimes both by and against people with psychiatric illnesses, as well as suicides. Critics say they return us to a day when psychiatrists arbitrarily decided who is normal and who isn't. . . ." (100)

What side of the debate are you on with this issue of AOTs—do "alarm bells go off" for you, as they might for the author, when a judge or medical health professional can force a patient to undergo care? Do experiences like that of Eric's family, as they watched their son's mental health rapidly and dramatically decline, shape your opinion? What lines would you draw?

3

How does Judy's statement "my son died with his civil liberties intact" powerfully and painfully illustrate the challenge of our current laws, which, in her husband Norm's words, "leave those who suffer to fend for themselves"? (108) What are the trade-offs for the benefits of adequate care?

4

Do you think encouraging patients, or everyone, really, to create a psychiatric advanced directive (PAD) or crisis plan could yield better outcomes and help citizens "leverage the law for treatment, not punishment"? (111)

## SECTIONS COVERED

### Chapter 6: The Kindness of Strangers

### Chapter 7: Early and Effective Intervention

1

Debbie's heartbreaking struggle and her cycle of broken care seem an all too common portrait. After shuffling from emergency rooms to the street and just off her prison sentence, Debbie is "free" but back in a cycle in which she struggles to thrive. What methods of long-term care and intervention would you suggest for her case? Do you think she'd benefit from pre- or post-adjudication programs? In what ways might these programs be challenging for someone with a mental illness?

2

Discuss Professor Elyn Saks's story, and how, even though she is "by no means 'cured,' Saks's biography offers evidence that relatively early, consistent intervention can turn the tide even for the most aggressive cases." (129) How does her story help to showcase how those with mental illness can still find fulfilling and successful careers, be parents and spouses, and achieve personal success?

3

"Just as a cancer diagnosis at stage one versus stage three offers hope for better outcomes, early intervention in cases of SMI is critical." In what ways is this analogy right on target? How is "untreated psychosis . . . actually toxic to the brain"? (129)

Why does early intervention matter so much?

4

How does our society treat the illness sufferer as an "other . . . devoid of humanity or any identity beyond their SMI"? (133) How is this attitude in turn toxic to the sufferer, "summarizing the entirety of their mind as 'sick'"?

(CONTINUED)

## Chapter 6: The Kindness of Strangers

## Chapter 7: Early and Effective Intervention

5

Were you shocked to read of the struggles of children, some in elementary school, with mental illness? How does early intervention seem to impact their futures in particular? Did any of the stories or individuals move you or shock you? Why must we shift our focus to this crucial development window to support our youngest citizens?

6

"Hope is at the core of Dr. Dixon's work with OnTrackNY. The New York-based program . . . helps young people showing early signs of mental illness to achieve their goals in school, work, and relationships." (136)

How might a program like OnTrackNY serve as a model for other communities? Is the level of practicality and attitude vital? What are they getting "right" and how might it compare with more reactive models like AOT?

7

What is *overly aggressive pruning*—and why could it be so consequential to the adolescent mind? Can it be reversed or treated? (140)

8

After reading this book, or drawing from your own experiences, what advice would you give other families struggling with mental illness? Is a realistic and proactive approach the best method for results (never giving up, advocating, staying informed on rights and new treatments)? Or what seems to be the author's essential advice?



## SECTIONS COVERED

### Chapter 8: Strength in (Small) Numbers, or America Is Waking Up Chapter 9: Going Home

1

"A mother whose son has SMI asked me, 'Why is this okay? Where is the outrage? The ribbons, the races, and the ice bucket challenges?'" (149)  
How would you answer this cry?

2

"We just substituted the local asylum for an 'indoor' one called the Los Angeles County Jail and an 'outdoor' asylum called skid row." (150)  
After reading this book, would you agree that we as a society have just "transinstitutionalized" our sickest citizens?

3

Using Trieste as an example, how are other cities outside the U.S. embracing community-centered care instead of a pipeline model? What have their results looked like? Could such a model work in the U.S.? What would be the challenges? (152)

4

In what practical ways did the Affordable Care Act begin to alleviate some of the trickiest hurdles to seeking care for mental illness?

5

Did you find it moving and fitting that the author chose to open and close the book with a scene with his sister Merle? After many years, why did the author need to "go home"—and what was waiting for him there? (169)

6

Did you find the author's survey of mental illness ultimately hopeful, and if so, in what ways? What is the heavy lifting still to be done? What aspects of care and perception need more intensive and meaningful work? Are you hopeful that as the science and social policy evolve, we will have a better guideline for understanding what causes mental disturbances? Is this hope realistic? Why or why not, and what stands in the way?

7

How do you think the resources section at the end of the book and organizations like NAMI, Mental Health America, Treatment Advocacy Center, and others, will benefit families looking for help and guidance?