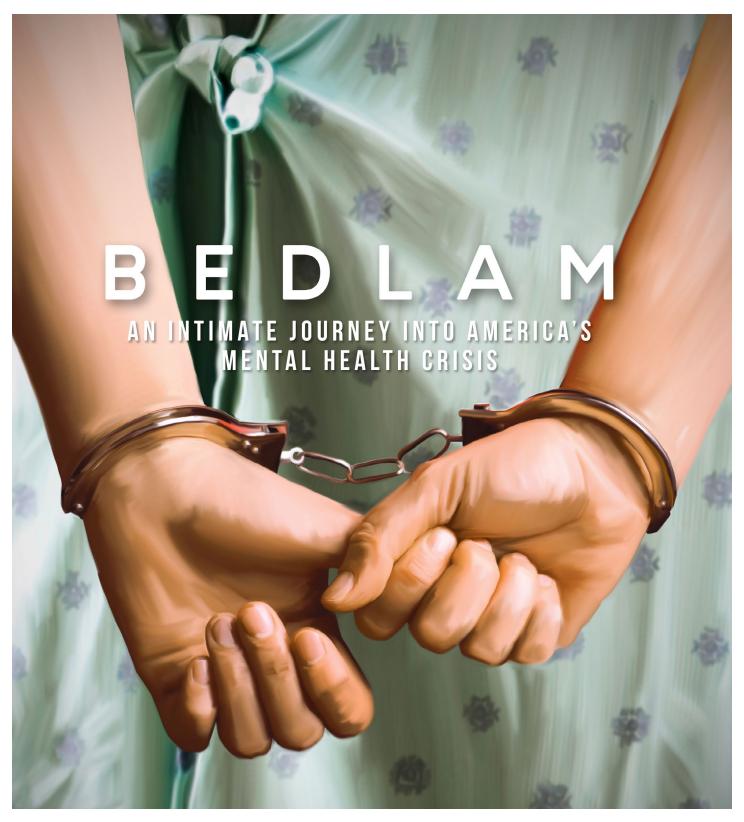


# **DISCUSSION GUIDE**





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# **USING THIS GUIDE**



This discussion guide for *Bedlam* is a tool to inform and prepare you to facilitate and organize Indie Lens Pop-Up events. This guide includes tips for hosting screenings, background information to deepen understanding of issues and topics in the film, and engagement strategies to inspire and foster conversation.

The film *Bedlam* offers an opportunity to shift the understanding of the crisis in care for people with serious mental illness in the United States and discuss better ways to support mental health in our communities. This guide, created by *Independent Lens*, is designed for people who want to engage more deeply with the issues after watching the film. It provides viewers with background information and helpful resources for learning more about America's mental health crisis. It also offers community leaders advice for organizing discussions through the Indie Lens Pop-Up screening series and activities for people called to action by the film. Through community engagement with the film, we hope viewers will help:

- Decriminalize serious mental illness and foster conversation about beds not bars for people with serious mental illness.
- Advocate for better treatments on par with other fields of medicine.
- · Address homelessness for people with serious mental illnesses.
- · Destigmatize mental illness.

### Overview of Indie Lens Pop-Up Series

Indie Lens Pop-Up is a neighborhood series that brings people together for film screenings and community-driven conversations. Featuring documentaries seen on PBS's Independent Lens, Indie Lens Pop-Up draws local residents, leaders, and organizations together to discuss what matters most, from newsworthy topics and social issues, to family and community relationships. Make friends, share stories, and join the conversation at an Indie Lens Pop-Up screening near you: bit.ly/ILPOP-Screenings

### **Neighbor Theme**

This season, Indie Lens Pop-Up builds on its theme of "neighborhood" by asking audiences: What's your vision for your neighborhood? As community members increasingly experience polarization and division in their everyday lives, we invite neighbors to come together at events across the country to hear diverse stories, practice listening with acceptance and openness, and build communities where all belong and feel welcomed.



# **ABOUT THE FILM**



### How to Watch the Film

Indie Lens Pop-Up community screenings:

March 2-April 12, 2020

PBS Independent Lens Premiere:

**April 13, 2020** 

Screening online at video.pbs.org:

**April 13–May 12, 2020** 

Deeply affected by the death of his sister who struggled with mental illness, psychiatrist Ken Rosenberg takes on the role of filmmaker to examine a national health crisis. *Bedlam* follows the poignant stories of people grappling with schizophrenia, bipolar disorder, and other chronic psychiatric conditions. When untreated, their symptoms push them into the path of police officers, emergency room doctors and nurses, lawyers, and prison guards. Over the course of five years, Dr. Rosenberg takes us inside Los Angeles County's overwhelmed and vastly underresourced psychiatric ER, a nearby jail housing thousands of psychiatric patients, and the homes—and homeless encampments—of people suffering from serious mental illness, where silence and shame often worsen the suffering.



# LETTER FROM THE FILMMAKER



When I was 14 years old, my wise and loving sister developed schizophrenia. Her mental illness, compounded by my parents' denial and shame, tore at the very fabric of our family. I became a psychiatrist because of my sister, and I directed and co-wrote this film because I wanted to understand and tell our story. Over the years, I have come to see that my family's tragedy is an American tragedy, my family's shame is America's great secret.

One in four families in the United States experiences serious mental illness. And yet our country has turned its back on this desperate population. By the time I became a psychiatrist, half a million state mental hospital beds had been lost, and medical research had hardly advanced since the 1950s. Today, our system for caring for people with serious mental illness has only gotten more tragic. Hundreds of thousands of Americans who are mentally ill live on the streets and in our jails and prisons, and half of the people killed by the police suffer from mental illness.

I decided to find out how this tragedy occurred, how we came to neglect our neediest patients. I reached out to author and mental health advocate E. Fuller Torrey, M.D., who told me, "Go west." So I returned to the city where I'd begun my psychiatry training, Los Angeles—where 20,000 people with mental illness live on the streets; which has the largest mental institution in the nation, the Los Angeles County Jail Twin Towers Correctional Facility; and where the only refuge for many is one of the most highly regarded psychiatric emergency rooms in the country, at the Los Angeles County+USC (LAC+USC) Medical Center. There, I began my chronicle of what it means to live with mental illness in America today.

# "I decided to find out how this tragedy occurred, how we came to neglect our neediest patients."

In five years of filming, I met hundreds of patients and their families, ultimately focusing on a small number of courageous people willing to share their stories, including Johanna, Monte, Todd, and Delilah, as well as a few dedicated medical professionals, whose experiences offered a window into the calamity of our broken system. I was joined on my journey by fellow doctors and filmmakers, family members, and activists to shed light on what Dr. Torrey has described as the greatest social crisis of our time.

The result is a film called *Bedlam*, named for the world's oldest mental hospital, Bethlem Royal Hospital in Beckenham, England, whose name has come to embody chaos and madness. It is my fervent hope that this film will help spark a national conversation to address how we might fix our system for caring for people with serious mental illness. The most powerful lesson I have learned is that none of us can solve this problem alone. We can only fix it as an outraged, outspoken, unashamed, and undeterred community.

-Kenneth Paul Rosenberg, Director, Bedlam



# PEOPLE IN THE FILM



## DR. KEN Rosenberg

**Dr. Ken Rosenberg** is a psychiatrist, speaker, author, and filmmaker. His sister Merle's struggle with mental illness had a profound impact on his life. In addition to his private practice in treatment of behavioral and addictive disorders, he is an award-winning filmmaker who has produced many titles on health. His recent book *Bedlam: An Intimate Journey into America's Mental Health Crisis* is based on the film.



### **JOHANNA**

Johanna is a thoughtful 23-year-old college student diagnosed with bipolar disorder. Like many managing mental illness, she struggles to balance the symptoms of her illness with the side effects of the medication that's meant to treat it.



### **MONTE**

Monte, described by his friends and family as a giant teddy bear, manages schizoaffective disorder. He was incarcerated for the first time at age 19 during a psychotic episode. His experiences in the Los Angeles County Jail left him with a deep-seated fear of hospitals and law enforcement.



### PATRISSE CILLINRS\*

Patrisse Cullors is Monte's sister and a co-founder of the Black Lives Matter movement. Informed by her brother's experience, she advocates for an end to police violence and mass incarceration against the Black community and people with mental illness. Together with the Reform LA Jails Coalition, she successfully convinced Los Angeles County to cancel the construction of a new mental health facility housed in a jail.



### TODE

**Todd** has survived more than a decade living on the streets of Los Angeles through resourcefulness and sheer will. He manages bipolar disorder as well as HIV, which he contracted using street drugs. Starting in his 20s, he spent two decades in a prison cell. With the help of the nonprofit organization LAMP Community, he works to find stable housing.



### **DELILAH**

**Delilah** is an 11-year-old girl who struggles with depression after being bullied at school. She has previously attempted suicide, and her teacher found a note describing suicidal thoughts, prompting her mother, Gloria, to bring her to LAC+USC Medical Center's psychiatric ER for treatment.



### DR. MCGHEE\*

**Dr. McGhee** was a doctor at the LAC+USC Medical Center's psychiatry emergency rooms in Los Angeles. Like Dr. Rosenberg, she is personally connected to her work through her own family's experience with mental illness. Fed up with the inability to provide proper care to her patients under the current mental health care system, she ultimately resigned.



DR. DIAS\*

**Dr. Dias** was head of psychiatry and child and adolescent psychiatry at the LAC+USC Medical Center, where he ran one of the busiest psychiatric ERs in the country. He went on to join the advocates pressing for community-based solutions to the crisis in Los Angeles instead of construction of a "mental health jail."



# DR. FULLER

**Dr. Fuller Torrey** is a research psychiatrist specializing in schizophrenia and bipolar disorder who has authored more than 20 books on the subject of mental health. He is a leading advocate for mental health care reform and is the founder of the Treatment Advocacy Center, which served as a key resource in the development of this guide.

\* Section may contain plot disclosures



#### **What Is Serious Mental Illness?**

People use the term *mental health* to refer to a wide range of mental and emotional conditions. It is important to note that the film *Bedlam* focuses on serious mental illness (SMI), an industry classification that encompasses schizophrenia, disabling mood and thought disorders, severe bipolar disorder, and severe depression. In children under 18 years of age, the term *serious emotional disorder* is used instead.

Unlike other health conditions, SMIs are diagnosed by their symptoms, not, for example, with a blood test or a brain scan (not yet at least). The symptoms of bipolar disorder include periods of mania—high energy, sleeplessness, grandiosity, and often irritability—alternating with periods of severe depression. The symptoms of schizophrenia include hallucinations and delusions such as hearing voices.

Policy makers and doctors use these terms in order to direct resources to the most severe cases of mental illness. The SMI classification does not include disabling panic attacks, disruptive personality disorders, post-traumatic stress disorder, or substance abuse disorders (although some argue that it should). It also does not include neurological conditions with a biological cause, such as Alzheimer's.

The brain remains one of the most mysterious parts of the body. Serious mental illness has no known cause, although research points to several influencing factors in its development. Biology and gene variations appear to play a role, as does stress due to trauma, such as poverty, homelessness, incarceration, and substance abuse. The combination of these stress factors seems to multiply their harmful effects on mental health—for example, about one in four people with an SMI also has a co-occurring substance abuse disorder.<sup>2</sup> However, much more research is needed to understand, diagnose, and treat serious mental illness.

#### Sources:

- Rosenberg, K. P. (2019). Bedlam: An Intimate Journey into America's Mental Health Crisis. New York, NY: Penguin Random House.
- <sup>2</sup> drugabuse.gov/publications/research-reports/common-comorbiditiessubstance-use-disorders/part-1-connection-between-substance-use-disordersmental-illness

### A Gap in Mental Health Treatment

The number of people seeking mental health care is on the rise in the United States. Yet the number of mental health professionals available to treat them is falling short. People in need of care face long waitlists to see a provider, and, like Dr. McGhee in the film, providers complain of overwhelming workloads and burnout. The result is a gap in treatment that leaves people without the ongoing preventive care necessary to manage serious mental illness.

There is a shortage of mental health professionals everywhere, but the problem is especially felt in rural areas. Among nonmetropolitan counties, 65 percent do not have a psychiatrist (an M.D. who specializes in mental, emotional, or behavioral disorders and who can and can prescribe medication), and almost half do not have a psychologist (a therapist whose focus is cognitive and behavioral issues; a psychologist cannot prescribe medication). People who live in rural communities, including many on Native American reservations, often have to travel far for treatment, making preventive care unrealistic. And when mental health goes untreated, risks of substance abuse and suicide increase. Currently, the suicide rate in rural communities is disproportionately high and on the rise.<sup>3</sup>

More than half of mental illness emerges before age 14. Early intervention can slow its progression and limit the disabling effects across a lifetime. The treatment gap, however, extends to youth mental health care as well. At least 85 percent of children in need of treatment do not get it. With suicide now the second leading cause of death for children and adults aged 10 through 34, the consequences of not receiving care can be life-threatening.<sup>4</sup>

In response to the shortage, colleges are stepping up their efforts to recruit psychiatry students, and nonprofit organizations are training peer specialists to provide additional support. For example, the state of Texas, which has a severe shortage of mental health providers, offers a certification for peer specialists and covers their services through the state Medicaid program. Studies show that peer specialists are effective in helping reduce the number of stays at psychiatric inpatient facilities.<sup>5</sup>

- <sup>3</sup> cnn.com/2018/06/20/health/mental-health-rural-areas-issues-trnd/index.html#
- ssir.org/articles/entry/the\_crisis\_of\_youth\_mental\_health
- <sup>5</sup> npr.org/sections/health-shots/2017/07/11/536501069/in-texas-people-with-mental-illness-are-finding-work-helping-peers



### **Shortage of Beds**

When faced with a mental health crisis, patients increasingly rely on psychiatric ERs, like the one at LAC+USC Medical Center featured in the film. According to the National Council for Behavioral Health, the number of patients going to the ER for psychiatric services over a recent three-year period increased by 42 percent.<sup>6</sup> The overall increase is occurring at the same time that access to preventive care has lagged and the number of beds at inpatient psychiatric facilities has dwindled.

Because of the shortage of beds, patients in psychiatric ERs who need further treatment at an inpatient psychiatric facility must wait until a bed becomes available. Those with the means to pay for the expense—such treatment can run \$30,000 a month—have more options to find an available bed, as do those whose health insurance will cover it. Those who cannot afford to pay, have poorer health insurance, or are on Medicaid, which does not cover treatment in an inpatient psychiatric facility for most adults, have extremely few options.

A 2016 national tally by the Treatment Advocacy Center put the number of public beds available in the United States at 37,679. That's a state average of 11.7 beds per 100,000 people, far below the recommended 40 to 60 beds.<sup>7</sup> To learn how many are available in your state, see this map: treatmentadvocacycenter. org/browse-by-state.

At their peak in 1955, state psychiatric facilities cared for about 560,000 patients nationally. That's in large part thanks to advocate Dorothea Dix, who began speaking out against the neglectful and inhumane treatment of people with mental illness in the 1840s. Over the next 40 years, Dix lobbied Congress to establish 32 state hospitals (also called asylums or institutions) for people with mental illness that provided custodial care.

Asylums developed a reputation for inhumane treatment due to controversial practices such as insulin-induced comas, electroshock therapy, and lobotomies (a surgery that removes parts of the brain). John F. Kennedy's sister, Rosemary Kennedy, underwent a lobotomy that left her brain and mind in worse shape. As president, he passed the 1963 Community Mental Healthcare Act, which transferred funding for mental health care from states to the federal government. The law envisioned a progressive form of mental health care that offered treatment at mental health outpatient centers in patients' local communities, rather than at state inpatient facilities.

When Ronald Reagan took office, he transferred the responsibility of funding mental health care back to the states. The vision of community-based mental health care was never fully realized, yet deinstitutionalization continued. By the 1990s, the United States had lost 90 percent of its beds for the treatment of persons with mental illnesses.

In 2008, during the passage of the Affordable Care Act, Congressmen Edward Kennedy and Patrick Kennedy, who is featured in the film, passed the Mental Health Parity Act. The law requires that insurance companies cover mental health care and substance abuse counseling at an amount equal to the coverage of physical health care costs.8 The law has been critical in protecting people with serious mental illness from discrimination in health care coverage.

#### Sources:

- health.usnews.com/health-care/patient-advice/articles/2018-05-25/whats-the-answer-to-the-shortage-of-mental-health-care-providers
- 7 pbs.org/newshour/nation/amid-shortage-psychiatric-beds-mentally-ill-facelong-waits-treatment
- 8 www.samhsa.gov/homelessness-programs-resources/hpr-resources/jfk's-legacy-community-based-care

### Lack of Innovation in Medication

In the 1950s, psychiatrists began prescribing the first antipsychotic drugs, including Lithium and Thorazine, which are still used today to treat symptoms of psychosis and mood disorders. At the time, the expectation was that advances in pharmaceuticals would replace the need for institutionalized care for people with mental illness. Thirty years later, the development of Prozac and other SSRIs (selective serotonin reuptake inhibitors) made it possible to treat depression. But otherwise, pharmaceutical innovation has been relatively underwhelming.

Lately, funding for research into new mental health treatments has all but dried up. Despite the growing demand, pharmaceutical companies, which develop most of the new drugs, have pulled back on neuroscience research. One study reported that in larger drug firms, the number of research programs focused on psychopharmacological drugs has shrunk by 70 percent over the past decade.9 Research on the brain is expensive, and the payoff is uncertain. Much of the industry has deemed it too risky. Instead, when patents on existing medications run out, companies opt to make minor tweaks to existing formulas and remarket them under new patents. The result is a lot of drugs that do similar things.

Academic researchers funded by philanthropy and the federal government can afford to take more risks than for-profit companies. However, funding has proven inadequate and is declining in key areas. Although the funds for veteran and child mental health care increased in the 2017 federal budget, both the Substance Abuse and Mental Health Services Administration (SAMHSA) and the National Institute of Mental Health (NIMH), which are responsible for grant funding for research, experienced cuts.<sup>10</sup> Philanthropic funding exists, but is small compared with fundraising efforts for other illnesses, for example, for cancer research.



And finally, the side effects of medications prescribed for SMIs are a significant concern. Sometimes, the side effects pose more of a risk to the patient than the mental health disorder. For example, metabolic effects cause patients to gain weight, increasing risks related to obesity and diabetes. According to the SAMHSA, up to 83 percent of people with SMI are overweight or obese—increasing their risk for heart disease. Many, like Johanna, stop taking their medications because they do not feel better or the side effects become intolerable.

#### Sources:

- theguardian.com/society/2016/jan/27/prozac-next-psychiatric-wonder-drugresearch-medicine-mental-illness
- <sup>10</sup> npr.org/sections/thetwo-way/2018/02/15/586095437/trump-calls-for-mental-health-action-after-shooting-his-budget-would-cut-program
- 11 integration.samhsa.gov/health-wellness/samhsa-10x10

### **Police as First Responders**

In the event of a mental health emergency, police are typically the first to respond to 911 calls for support. It is a myth that serious mental illness causes people to be more violent. In fact, studies show that people with an SMI are more likely to be victims of crime. Yet they are often treated like criminals.

During these encounters, data suggest that police officers are able to deescalate the situation about 20 percent of the time. However, about 80 percent of the time, officers transport the individual in crisis to either a hospital or a jail. In 2017, law enforcement agencies spent \$918 million and 21 percent of their time responding to and transferring people with serious mental illness, according to a 2019 survey from the Treatment Advocacy Center.<sup>13</sup>

Advocates point out that police are not health professionals and the responsibility for transporting people in a health emergency should not fall to them. Involvement with the police puts people with serious mental illness at greater risk for arrest or worse—21 percent of all 992 people shot and killed by police in 2018 had a mental illness. The problem is of particular concern for Black males like Monte who are already at risk due to racial bias in policing. The 2014 killing of Ezell Ford, a 25-year-old Black man who was diagnosed with schizophrenia and bipolar disorder, is a tragic example.

More police departments are mandating crisis intervention training (CIT) for their officers to prepare them for these encounters. CIT provides strategies for deescalating situations involving someone with a serious mental illness. After Florida's Miami-Dade County mandated CIT for its officers, it was able to decrease arrests of people with mental illness from 20,000 a year to 138, and fatal shootings dropped 90 percent. The decline in arrests and incarcerations enabled the county to close a jail and save taxpayers \$12 million a year.<sup>15</sup>

#### Sources:

- 12 mentalhealth.gov/basics/mental-health-myths-facts
- 13 treatmentadvocacycenter.org/storage/documents/Road-Runners.pdf
- <sup>14</sup> washingtonpost.com/graphics/2019/national/police-shootings-2019/
- 15 theatlantic.com/politics/archive/2017/08/how-mental-health-training-for-police-can-save-livesand-taxpayer-dollars/536520/

### **Incarcerating People With Mental Illness**

In the United States, 2 million people with mental illness are booked into jails each year. In every county throughout the nation, jails hold more people with mental illness than do local inpatient psychiatric units. As the number of public psychiatric beds has decreased, the rate of incarceration of people with mental illness has increased. In the 1970s, about 5 percent of those incarcerated had a serious mental illness. By 2014, 20 percent of the county jail population and 15 percent of the state prison population had an SMI.

The data suggests that as psychiatric hospitals have disappeared, the United States has unwittingly transferred care of people with mental illness from health and human services departments to the criminal justice system. Jails are not environments where people with an SMI typically improve. Inmates and their families complain of not getting access to proper medication or treatment, and the isolation and confinement in a cell usually make symptoms worse.

People who have an untreated serious mental illness tend to stay in jail longer. For example, the average stay for all inmates at Rikers Island in New York City is 42 days, compared with 215 days for an inmate with a serious mental illness.<sup>18</sup> That means costs go up—some studies have shown that the cost to house and treat a person who is in jail or prison with a SMI can be twice as much as an incarcerated person without without SMI. And when individuals leave jail, they do so with a strike on their record, making it harder for them to get a job and find housing and more likely that they will end up back in jail.

Diversion programs such as mental health courts help people with an SMI avoid incarceration. Mental health courts require defendants to commit to treatment in exchange for expunging their record. Initial data show that the recidivism rate is less for people who go through mental health courts. However, those that require a state psychiatric bed for their treatment can still wind up waiting in jail until one becomes available.

- nami.org/learn-more/public-policy/jailing-people-with-mental-illness
- <sup>17</sup> treatmentadvocacycenter.org/evidence-and-research/learn-more-about/3695
- <sup>18</sup> nytimes.com/1998/03/05/us/asylums-behind-bars-special-report-prisons-replace-hospitals-for-nation-s.html
- <sup>19</sup> npr.org/sections/health-shots/2015/12/16/459823010/mental-health-courtsare-popular-but-are-they-effective



### **Mandatory Treatment**

It is not uncommon for people with serious mental illness to deny they are sick or to refuse treatment, as Dr. Rosenberg's sister Merle did. In fact, doctors consider this type of thinking, which they call anosognosia, a symptom of the delusions caused by the illness. Unfortunately, what to do when a loved one refuses treatment is a question that many families face.

Mandatory treatment largely fell out of favor in the 1960s at the onset of deinstitutionalization. Today, it is a topic that still generates much debate. Opponents say that mandatory treatment infringes on the autonomy and civil liberties of people living with mental illness and returns to the days when psychiatrists defined what is normal or abnormal behavior. Proponents argue that it can save lives, especially from suicide, and that it is inhumane to allow sick people to languish in jails and on the streets without support.

In certain circumstances, a judge can order that someone receive mental health treatment at a physician's request. If the individual has been arrested, the order would come from a mental health court, and noncompliance could send the patient back to jail. If the individual is not under arrest, a civil judge could order short-term hospitalization (usually 72 hours) or longer-term hospitalization if, for example, there is an imminent danger. In severe cases, family members can file for a conservatorship or guardianship that grants them decision-making power over the individual's treatment and finances.

In 47 states—all except Connecticut, Maryland, and Massachusetts—and the District of Columbia, a judge can order assisted outpatient treatment (AOT).<sup>20</sup> This form of treatment assigns a team of doctors, nurses, public defenders, case workers, and counselors to support the individual in maintaining compliance while living in the community. Unlike with mental health courts, individuals in AOT cannot be arrested for noncompliance, although they could be hospitalized, which often proves to be a motivating factor. Of the participants in New York state's AOT, fewer experienced hospitalization, homelessness, arrests, or incarceration than they did three years prior to receiving AOT.<sup>21</sup>

Another, more collaborative approach is known as a psychiatric advance directive (PAD), which is a written, legal agreement whereby patients outline which types of treatment they consent to and which types they do not consent to in the event they become too sick to advocate for themselves. Completed while the patient is of sound mind, a PAD can also include the name of a person to act as power of attorney over treatment decisions when the need arises. PADs are possible in all states and expressly authorized in 27 states.<sup>22</sup> For information on your state, visit the National Resource Center on Psychiatric Advance Directives: nrc-pad.org/states.

#### Sources:

- 20 treatmentadvocacycenter.org/fixing-the-system/promoting-assistedoutpatient-treatment
- $^{21}\ treatment advocacy center. or g/storage/documents/a ot-one-pager. pdf$
- <sup>22</sup> nytimes.com/2018/12/03/health/psychiatric-advanced-directives.html

### **Homelessness**

Living with a serious mental illness can make it more difficult to maintain both a job and the close relationships necessary to keep stable housing. Without public psychiatric beds available, people too often end up homeless. An estimated 24 to 33 percent of homeless people are individuals with SMIs that are untreated. Homelessness is typically associated with major metropolitan areas, but it exists in smaller cities and towns too. In Roanoke, Virginia, for example, the homeless population increased 363 percent between 1987 and 2007, with 70 percent of the population having some history of mental illness.<sup>23</sup>

On the streets, people with mental illness are at risk for becoming victims of crimes or getting arrested. Their health conditions deteriorate without treatment, and many turn to self-medicating with street drugs and alcohol to cope, which can exacerbate their symptoms. Living on the streets is unsafe for anyone; it is especially dangerous for people with an SMI, who require a healthy lifestyle to manage their illness.

When someone with an SMI enters the system through either a psychiatric ER visit or a stay in jail, those institutions typically do not take responsibility for making sure that patient has housing upon release. Advocates would like to see more wraparound care, which would provide assistance and follow-up to make sure patients have the stable housing necessary to get well and sustain necessary treatment.

Support with finding housing is a core component of the approach used in Trieste, Italy, a model that's been recognized by the World Health Organization as exemplary. Trieste's approach is credited with little homelessness, low incarceration rates for people with mental illness, and few psychiatric facilities. The model focuses on something called recovery-oriented care that prioritizes wraparound services like housing support, wellness checks, and reimbursement systems that pay doctors for results rather than number of services. A group of Los Angeles County representatives have studied and recently made recommendations based on the Trieste model.<sup>24</sup>

- 23 treatmentadvocacycenter.org/evidence-and-research/learn-more-about/3629serious-mental-illness-and-homelessness
- <sup>24</sup> file.lacounty.gov/SDSInter/dmh/1054552\_TriesteConceptPaper-4-18-2019FINAL.pdf



### Stigma and Shame

Shame around serious mental illness results from a social stigma that makes people embarrassed to admit to themselves or talk to others about their mental illness. Shame is dangerous because it makes people less likely to seek treatment or advocate for improved care.

Stigma affects all types of families, but many people of color say the stigma in their communities is more acute than in White communities.<sup>25</sup> The result is that fewer people of color receive treatment for mental health conditions. For example, about 30 percent of Black adults with mental illness receive treatment compared with 43 percent on average.<sup>26</sup> A lack of diversity in the mental health profession is also a factor. About 90 percent of mental health clinicians are White,<sup>27</sup> making cultural competency a concern for people of color seeking care. Research shows that providers are more likely to see a person of color as sicker than a White person with the same clinical presentation.<sup>28</sup> Mistrust in the system only adds to the stigma around seeking treatment.

Public education programs are one strategy for decreasing the stigma around mental health. Healthy Men Michigan is an example of an education campaign that works to decrease the stigma among an at-risk population; suicide is the leading cause of injury death among Michigan men.<sup>29</sup> The program offers free online screening services and referrals to treatment. Awareness months are also a tool for increasing public discussion and information—May is Mental Health Awareness Month in the United States.

- <sup>25</sup> ncbi.nlm.nih.gov/pmc/articles/PMC5568160/
- $^{26}\ nami.org/find\hbox{-}support/diverse-communities/african-americans$
- <sup>27</sup> apa.org/pi/families/resources/mental-health-needs.pdf
- <sup>28</sup> sciencedirect.com/science/article/abs/pii/0165032796000286
- 29 health.usnews.com/health-care/patient-advice/articles/2018-02-09/how-can-men-fight-the-stigma-of-dealing-with-mental-health-problems



# DISCUSSING THE FILM

Community conversations are a critical part of shifting the understanding about mental illness. These questions can help you think more about the main ideas in the film and discuss those ideas with other viewers, either in person or online at #BedlamFilmPBS. For event organizers using these questions in panel discussions, it is helpful to review the questions with panelists in advance to make sure they feel prepared to answer.

- The film Bedlam is primarily shot in Los Angeles. How does mental health care locally compare with the issues facing Los Angeles, such as bed shortages, incarceration, and homelessness?
- 2. Which scenes, characters, and information from the film made an impact on you? Why?
- 3. Why do you think Dr. Rosenberg decided to include himself and his family's struggle with mental illness in the film?
- 4. "You can't fix what you can't face," says Dr. Rosenberg when he visits his sister Merle's bedroom. What do you think he means by this? What are we not facing on a personal and social level when it comes to serious mental illness?
- 5. What role do shame and stigma play in America's mental health crisis?
- 6. Do you think people experience the stigma of mental illness differently depending on their race or ethnicity, gender, sexuality, or economic status? If so, how?
- 7. Do you think the stigma surrounding mental illness is changing? What do you think would help reduce shame for those with serious mental illness?
- **8.** What did you hear Johanna, Monte, Todd, and Delilah say they wanted for their lives? How did their mental illnesses get in the way of them fulfilling their goals?
- 9. What is your response to Johanna's experiences with the medication prescribed to her? What can we as individuals do to encourage more advances in the mental health therapies available to people living with serious mental illness?
- 10. Mandatory treatment for those who refuse care is a contentious issue for many. Opponents say it infringes upon the autonomy and civil liberties of people with mental illness; proponents say it saves lives and is more humane than letting people languish in jails or on the street. What is your opinion on mandatory treatment?
- 11. According to the National Institute on Drug Abuse, a quarter of the people living with serious mental illness also have a substance abuse disorder. Why do you think this is? How are mental illness and substance abuse related?
- **12.** "We just keep going around in circles, and we get nothing," says Todd in the film. How would you describe the cycle that Todd was caught in? What do you think it takes to break out?

- **13.** According to the Treatment Advocacy Center, as much as one-third of the homeless population has a serious mental illness. What impact did you see housing have on someone's ability to access quality health care?
- 14. What are the potential benefits and risks of having police be the responders in mental health emergencies? What are some alternatives that cities could provide to individuals and families in times of crisis?
- **15.** Both Monte and Todd had experience with the criminal justice system. What factors contributed to better care for Monte than for Todd?
- 16. In every county in the United States, there are more people with serious mental illness living in jails than in psychiatric hospitals. What is your response to this fact? How are local leaders responding to the large number of people with mental illness living in our county jails?
- 17. How do mental health courts work differently from traditional courts? Does our community have a mental health court?
- **18.** What advocacy exists in the community for mental health care? What would you like to see more of?
- 19. "I didn't know how to cope," Delilah says about her emotions and the bullying she experienced at school. How can we better provide children with the early intervention and treatment they need to cope with emotional disorders?
- **20.** What support is needed for the families of people who have a serious mental illness?
- 21. What advice would you give to service providers and policy makers about how to address the issues contributing to the mental health crisis in America?
- **22.** What is needed to create a more welcoming community for our neighbors that live with serious mental illness?
- 23. In this season of Indie Lens Pop-Up, we are asking audiences to share with us their vision for the community. Given what you've seen in the film, what is your vision for the community when it comes to mental health?



# HOSTING A COMMUNITY SCREENING EVENT



Screening the film for a live audience is an ideal way to raise the profile of the issue in your community. We recommend you partner with local organizations and invite speakers familiar with the topic to lead a discussion with your audience. These suggestions can help you find relevant partners or speakers to include in a local screening event.

- Invite local individuals living with serious mental illness and their families and service providers to share their experiences accessing treatment in the community. The best way to connect with individuals and their families is to partner with a local chapter of the National Alliance on Mental Illness (NAMI). The organization has been a strong supporter of the film and a leading advocate for people with mental illness. It may also be able to help you find local mental health professionals with experience working in psychiatric ERs. Find your local NAMI chapter by state here: nami.org/Find-Your-Local-NAMI. You can also search for contacts through the following:
  - Treatment directory at SAMHSA: findtreatment.gov
  - National Association of Rural Mental Health: narmh.org/about.html
  - BEAM community: beam.community
- Prepare community members and venue staff to support audiences who may be upset or triggered by sensitive material addressed in the film. Discourage gatekeeping by priming venue staff on the subject matter if possible.

- Look for advocates in your community working on the issues of mental health and homelessness or criminal justice reform.
   Reach out to local homeless shelters or to the National Homeless Coalition to see if there is a speaker near you who is knowledgeable about serious mental illness: nationalhomeless. org/about-us/projects/faces. Also look for local organizations that may have campaigns related to area jails and prisons, similar to the Reform LA Jails Coalition featured in the film. And finally, search your local newspaper for community groups that are active.
- Check to see if your local police department has a crisis
   intervention team. Trained officers may be able to talk about how
   reforms in policing are impacting incarceration rates among people
   with mental illness. For a national map of departments that have
   participated in CIT trainings, visit: cit.memphis.edu/citmap.
- Ask area public officials who work on health and human services
  to discuss proposed strategies for improving mental health in
  the community. Your county should have a department of public
  health and a board of supervisors that oversee policy decisions.
  Find a directory of state and local health departments here:
  cdc.gov/publichealthgateway/healthdirectories/index.html.



# **ENGAGING WITH THE FILM**



In addition to a community discussion, there are other ways to engage with the film that can help achieve the goals of breaking down stigma and improving mental health services. Here are some ideas to include in a public screening or to take on individually after watching the film:

- Help connect community members to organizations that provide free and low-cost support to people with mental illness by hosting a resource fair. For example, you could invite representatives from homeless shelters, housing assistance programs, and advocacy organizations, substance abuse counselors, suicide prevention groups, support groups for family members, therapy providers, and public defenders that work with mental health courts. The potential partners listed in the "Hosting a Community Screening Event" section above are good places to start. You could also check the GuideStar directory for organizations near you: guidestar.org.
- Organize a donation drive for homeless members of the community and drop the donations off at a local shelter.
   Commonly requested items include toiletries, over-the-counter medicine, stamps, linens, undergarments, and baby supplies. For more guidance on commonly requested items and information on how to organize a drive, see this resource from Homeless Connections: homelessconnections.net/pdf/TTH-Coordinating-a-Donation-Drive.pdf.
- Host an art therapy showcase featuring works by people living
  with serious mental illness. You can search for local centers or
  mental health facilities that use art therapy with their patients or
  put out a call for submissions. For inspiration, see the Not Alone
  Art & Poetry site from the NAMI: notalone.nami.org.

- Encourage people to research and discuss the issue more by coordinating a book club reading of Dr. Rosenberg's book Bedlam: An Intimate Journey into America's Mental Health Crisis, published in 2019 by Penguin Random House: penguinrandomhouse.com/books/602602/bedlam-by-kenneth-paul-rosenberg-md/. Dr. Torrey, who is interviewed in the film, also has a wide selection of books on serious mental illness: treatmentadvocacycenter.org/about-us/dr-e-fuller-torrey. In addition, Patrisse has published a memoir about her experiences fighting racism through the Black Lives Matter movement: patrissecullors.com/call-terrorist-black-lives-matter-memoir/.
- Create media content such as radio interviews, documentary shorts, and social photography campaigns to raise awareness about mental health in your community. Debut the work in May during Mental Health Awareness Month and/or throughout the year.
- Organize a community fundraiser for mental health research, such as a walk or gala. The NAMI provides guidance for those interested in fundraising: nami.org/Get-Involved/Donate-to-NAMI/Ways-of-Giving/Do-It-Yourself-(DIY). Also check out the NIMH's information on fundraising: nimh.nih.gov/about/connect-with-nimh/donate-tomental-health-research.shtml.



# RECOMMENDATIONS FOR SUPPORT

As you discuss the issue of mental health in your community, you may encounter someone that needs direct services. Here is some helpful information if the need arises:

#### 24-Hour Crisis Lines

 National Suicide Prevention Lifeline Call 1-800-273-TALK (8255);
 En Español 1-888-628-9454;

Crisis Text Line
 Text "HELLO" to 741741

TTY 1-800-799-4889.

Veterans Crisis Line Call 1-800-273-TALK (8255) and press 1 or text to 838255; TTY 1-800-799-4889

# Practical Advice for Persons with an SMI and Their Families

For more detailed advice from Dr. Rosenberg, see his book *Bedlam:* An Intimate Journey into America's Mental Health Crisis, page 181.

- Connect with advocates at the NAMI for solidarity, education, and advice and to find knowledgeable service providers. Reach NAMI's HelpLine at 1-800-950-6264 or visit nami.org.
- Develop a crisis plan by researching the resources available in the community, such as psychiatric ERs and mobile crisis units, and writing down phone numbers so you have them available before an emergency happens.
- Create a support team of family members, friends, and professionals who can help in times of crisis with rides to the hospital, meals, and simply kindness.
- Prioritize empathy and collaboration over tough love approaches to prevent alienation from the treatment necessary to help people maintain their mental health.
- Get psychiatric help by visiting an emergency room with a loved one, calling a crisis intervention team, or, if necessary, contacting the police and explaining the situation before they arrive.

# **RESOURCES**

- bedlamfilm.com Filmmaker website for the film Bedlam
- pbs.org/independentlens/films/bedlam Independent Lens website for the film Bedlam
- penguinrandomhouse.com/books/602602/bedlam-by-kennethpaul-rosenberg-md — the accompanying critically acclaimed book by Kenneth Paul Rosenberg, M.D., Bedlam: An Intimate Journey into America's Mental Health Crisis
- nami.org website for the National Alliance on Mental Illness, which provides people who have mental illness with information about treatments and services, including access
- treatmentadvocacycenter.org website of the Treatment Advocacy Center, which breaks down laws and policies by state
- nimh.nih.gov/index.shtml website of the National Institute of Mental Health, which is the federal agency responsible for mental health research
- samhsa.gov website for the Substance Abuse and Mental Health Services Administration, which is a public health agency within U.S. Department of Health and Human Services



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#### ITV

ITVS is a San Francisco-based nonprofit organization that has, for over 25 years, funded and partnered with a diverse range of documentary filmmakers to produce and distribute untold stories. ITVS incubates and co-produces these award-winning films and then airs them for free on PBS via our weekly series, *Independent Lens*, as well as other series through our digital platform, OVEE. ITVS is funded by the Corporation for Public Broadcasting. For more information, visit itvs.org.

#### **INDEPENDENT LENS**

Award-winning weekly series airing on PBS Monday nights at 10:00 PM. The acclaimed series, with Lois Vossen as executive producer, features documentaries united by the creative freedom, artistic achievement, and unflinching visions of independent filmmakers. Presented by ITVS, the series is funded by the Corporation for Public Broadcasting, a private corporation funded by the American people, with additional funding from PBS, the John D. and Catherine T. MacArthur Foundation, Wyncote Foundation, and the National Endowment for the Arts. For more visit pbs.org/independentlens.

Join the conversation:
With #BedlamFilmPBS and
#WeAreAllNeighbors at facebook.com/
independentlens and on Twitter
@IndependentLens.

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