

## Ken Rosenberg with Stephanie Tong

>> STEPHANIE TONG: Welcome to "Disability, Inc." I'm Stephanie Tong, Director of Parent and Family Engagement at INCLUDEnyc. Today, I have the great privilege of speaking with Dr. Kenneth Rosenberg about his film and book "Bedlam" as he shines light on America's mental health system. Dr. Rosenberg is first and foremost a psychiatrist with a specialty in addiction medicine. He's an author, speaker, and filmmaker. His books focus on a range of mental health topics, includes mental health activism, addiction, and relationships. He has been featured on NBC and CNN. He is a Peabody Award-winning producer and director. His films focus on a variety of mental health issues.

Welcome, Dr. Rosenberg. It was your film "Bedlam" which introduced us to your work, and you've been actively engaged in our mental health systems for decades. So we're really delighted to have you as an expert and help us better understand the mental health systems in America. Your breadth of work is wide-ranging today, but we want to focus a little bit on more of the access of services, navigating the mental health system, and as well as advocacy. So there's so much to unpack today, so why don't we go ahead and get started?

>> KENNETH ROSENBERG: Great, thanks so much for having me. Pleasure.

>> TONG: So I wanted to first talk a little bit about your film "Bedlam." You highlight several stories of those suffering from serious mental illness. As a professional who's worked in community mental health clinics, I felt a really wide range of emotions when I saw the film. I think one of the things I wanted to hear from you is what motivated you to write this film? Because I think I took a lot away from it. So I was just curious what motivated you?

>> ROSENBERG: Sure, so I'm a psychiatrist, and a filmmaker, and I'm a writer -- sometimes writer. And I think as a psychiatrist, I realized that this is really a great untold story of psychiatry, and it's one of the greatest social crises of our time -- of the 20th century, now 21st century. So I think that that was enough of a reason. I've made several films for HBO and PBS. Since medical school, I've directed films. This is maybe, what, the seventh film? I make one every five or ten years or so, in between my practice.

But I thought this was a particularly important one to make, because this film focused on people with severe mental illnesses, people who often are marginalized, criminalized, put in jails, live in streets, get just about the worst care -- and have the greatest need. So the question that I approached my film and book with was: Why has our country, and why has my profession abandoned; and how has my country and how has my profession abandoned our neediest citizens? That's why I wanted to make the film and write the book.

>> TONG: What do you hope people take away from the film and book?

>> ROSENBERG: Well, I think that firstly that we have abandoned these people. We've criminalized them, which is in and of itself criminal -- to put people in jail who ought to be in hospitals. To allow people to languish on the streets who ought to be in care of some sort. To give medications that are helpful, but not helpful enough, and are somewhat antiquated.

In the rest of medicine, if you have an illness, you get a cocktail or some kind of medicine or some kind of regimen that's just about two or three or five years old, for the most part; especially with diseases like cancer and cardiovascular disease. If you have a psychiatric illness,

you get a medicine which is maybe new, but it's based on a molecule that's decades old, and it's pretty much from the last century.

So I think that we have not done right by our fellow citizens with severe mental illness. Again, I'm talking about people with schizophrenia, bipolar disorder, suicidal depression. What I hope people get out of this is: What the heck? That's wrong, and we need to do something as citizens, because these are our loved ones. These are ourselves. These are a large segment of the population.

And the money is being spent very poorly, so even if you don't give a darn about anyone else except your taxes, you still should be outraged, because the money that is being used on putting people with mental illness in jail is astronomical. How much does it cost to put someone in jail with a mental illness? Close to \$100,000, perhaps. It's a lot of money. And that money could be used much more wisely on housing, and outpatient treatment, and community engagement, and enforcing sobriety -- all sorts of wraparound services that are much cheaper, much more efficient, and much more humane than jail and the streets.

>> TONG: And I appreciate your delving in your work on how we have to look at this as a holistic picture, right? That we have to really touch on a lot of the human pieces that we need to live, like housing, food. We all want to ideally live a productive life and work in some way. We want to all have quality health care, education, and all those things. It sounds like you're saying we need to look at all of those when we treat someone with severe mental illness. So why do you think we as a society have overlooked this, or brushed under the rug, or however we want to call it?

>> ROSENBERG: Many, many, many reasons. First of all, it's scary. Second of all, it's not easily treated. I don't think there's necessarily a conspiracy against treating people with severe mental illness, but the problems that they endure are complicated. How to get someone well who fights against getting well sometimes, because if you have a severe mental illness, sometimes you don't know that you're sick. And you certainly don't -- and sometimes for good reason -- don't want what the medical establishment has to offer you. So how do you deal with that?

So I think that it's largely the illnesses. It's largely that the illnesses are so formidable and so difficult, that we have kind of turned a blind eye. We've taken kind of a laissez-faire attitude. We used to indiscriminately, in my opinion, lock people up in very bad places. So now we don't do that, good for us, but we let them die in the jails and streets. It's not a great alternative, in my opinion.

>> TONG: Right, there has to be a happier medium than --

>> ROSENBERG: There has to be a better option than that. So I think the first and foremost reason we've done it is because these are very hard illnesses to treat, very hard to understand, they're complicated, they're costly, they cause a lot of trauma for the people who experience the illnesses and for their family members, and often for society. So I think we all want to do, so we often take the most expedient approach, which is to do nothing, and to let people kind of languish, as I say, in the jail and the streets.

Also, there's lots of prejudice out there. Lots of discrimination against people with mental illness, especially people with severe mental illness. People with severe mental illness, or mental illness of any sort, have a lot of shame. That's a third reason. They don't talk about it.

And when you don't talk about something, how the heck are we as a society going to fix it when we don't talk about it? We don't demand that there's better treatment. Can you imagine if we let people with Alzheimer's disease live in jails and streets? Their family members would say this is unacceptable. Senators, Congresspeople, would mount an offense immediately.

But somehow, when it has to do with severe mental illness, we kind of let it go. People don't speak up enough. People with the illnesses, family members, don't speak up enough. So they get kind of pushed aside. So I think there's many reasons why. But it's the illness, first and foremost. It's the obstacles to treatment. It's the shame associated with the illness. And it's the cost and complexity of the problem.

>> TONG: I think for the multiple reasons that you've mentioned, the complexities of it, and I think, as you mentioned, sometimes the shame, and it's not necessarily always a pretty disease or picture, right, or illness. And some of the behaviors that are exhibited, sometimes it can feel very difficult to connect with someone with maybe some severe mental illness, and some things that come out from that.

So I think one thing that came out from your film and book that caught my attention was the idea of acting early, and there are ways that caregivers and families can support individuals with mental illness, I think whether severe or not, early. What do you think are some signs that people can be observant of, these early signs?

>> ROSENBERG: Yeah, great question. I mean, we have made some good advances in the recognition of these illnesses. So one of the main approaches that the National Institute on Mental Health and other organizations is taking is early intervention. We don't have that many

advances in later intervention. But certainly, if we intervene early, it's much easier to treat any illness.

Forget about illnesses -- it's much easier taking care of any problem if you take care of it early on, you know? We try to take care of your smoking habit when you have like a few cigarettes. It's much easier than after you've been smoking two packs a day for 20 years. If you have any kind of cancer, it's much easier to treat that cancer at Stage 1 or Stage 0 than Stage 4. Likewise, you have this mental illness of any sort, specifically a severe mental illness like schizophrenia or serious bipolar disorder, it's best to treat that early.

And what are the signs you ask, of early -- of the illness? Well, the truth is, it's not -- I don't think it's for your listeners, anyone should be required to diagnose themselves or their family members. But first, if you have a suspicion you have a serious mental illness, you should go to your doctor. You should see a qualified psychiatrist. But early symptoms are magical thinking -- that's an early symptom of a psychotic disorder. Social withdrawal or social functioning or school functioning, if people are in school, or job functioning. Just kind of pulling back from people. It depends on the illness.

With an illness like schizophrenia, which is largely a thought disorder, disorder of thinking, people have magical thoughts, or paranoid thoughts. Doesn't really rise to the level of being a fulminant illness, but creates suspicion that something is wrong.

With a mood disorder, like bipolar disorder, people are more depressed and more moody than usual. They don't get out of bed. They might even have some passive suicidal ideation. They might feel life is hopeless and they're worthless. And they have this kind of mood

thing that they can't seem to get a handle on. It doesn't last for an hour a day, but it lasts for a long time.

And other major problems, like substance abuse. People use recreational drugs, but sometimes, that begins to take over. So you're not using the drug, the drug is doing you. The drug is running your life. You're not deciding it's time for a drink. The drink is saying: Wake up, it's time to have your drink. It's time to have some opiates. So I think those are some of the signs of the major illnesses that people could recognize.

But I think, honestly, Stephanie, whenever there's a question, whenever there's a problem, medical advice at this point is pretty easy to get. Wherever you live -- we're talking about New York City, there's an urgent care on every street corner. We have five or six really good psychiatric emergency rooms. We have a project called Thrive NYC. Thrive is an organization where people can get help, and phone numbers that people can call. Help is not that far away.

I think the bigger reason why people don't get early diagnosis, honestly, is that they're so ashamed and so afraid and they don't want to talk to anyone. As I say, the treatments aren't perfect. It's scary to see a psychiatrist. Scary to get a diagnosis. But I would say it's a lot scarier to live with untreated illness for years and years.

>> TONG: I think you bring up a good point: What can people expect, for example, when they have their first visit? I think sometimes the mystery of the process feels scary.

>> ROSENBERG: Yeah, I think it's tough, because I think that you want to find a good psychiatrist. Or you want to find a good counselor you can talk to. You want to find someone

who you feel respects you. You want to have some agency in the matter. You want to try to not get help in a busy emergency room, but get help from a counseling service or counseling center. I imagine that you have places that people can call, and I hope you'll give those numbers in New York City and around. National Alliance on Mental Illness is a great resource. Online, you can find so much.

But I think that how you deal with the intimidation of seeing a professional, and the fear of that, it's not easy, but I think you find someone who you can talk to, and someone you respect, and you kind of listen to that. We all get good advice from friends or health care professionals, and we often dismiss it if it doesn't fit with what we have in mind. But I would encourage your listeners, when they talk to a counselor or a psychologist or psychiatrist, to have an open mind about what the possibilities are. And not be so caught in the kind of shameful thinking about what if this is a disease? Just trying to be open to other people.

It's hard, it's hard. To be honest, psychiatrists in the past have not made it easier. Sometimes they have been very judgmental and not treated people necessarily well. There's truth in the fact that people don't feel so comfortable, necessarily, talking with just anyone about their severe or mild mental illness. But it's really important to do.

>> TONG: I think something that you brought up that led into my next question is -- talking about the connection and relationship that you start to feel when you first meet someone, and how can someone, maybe in the first, one, two visits or so, decide a little bit whether this person is someone they want to continue seeing?

>> ROSENBERG: Yeah. Well, again, you have a lot of professionals in the city. You have a lot of people you can talk -- I encourage people who are patients, consumers, if you will, to shop around. Especially when you're talking about mental health professionals, there's all kinds. I also encourage people to find someone who has really good credentials. Just because someone says "I'm a therapist, I can help you --" unfortunately, all health professionals say, "I'm the one -- I'm the only one who can help you." But that's not the case.

A lot of therapy, a lot of treating someone with a psychiatric illness has a lot to do with personal chemistry, and how you get along with them. But they could have degrees from the best medical centers, and you still could think they're a jerk and you don't want to talk to them. That's understandable. But you want to find a qualified person.

So what does that mean? At least a licensed social worker. Licensed in the state of New York. Licensed psychologist. Licensed psychiatrist. Someone who maybe is involved in a medical scepter that you respect, you feel comfortable with. Your PCP, your primary care physician, is often a good source of finding mental health care. And again, I think there's lots of good resources in New York through Thrive and NAMI (National Alliance on Mental Illness) that could really help direct you to find someone to talk to.

>> TONG: Sounds like sometimes shopping around, because I think sometimes a question that I get, even from friends, is: Do you have someone you could recommend me? And that's a tough question to answer. I think this is one of the reasons why I pose what should people look for, and kind of how do they find the right fit for them.

>> ROSENBERG: It's tough, because if you've never met a psychologist or social worker or therapist, psychiatrist, you don't know what to expect. But you have to -- it's complicated, isn't it, Stephanie? Because on one hand, you have to have an open mind. On the other hand, you have to be discriminating. If something seems wrong or unethical or too expensive or too weird, find the next person.

>> TONG: It sounds like feeling self-agency, right? You don't have to just go with the first person on your insurance, or that you can change and make a list of what you're looking for.

>> ROSENBERG: Absolutely.

>> TONG: Yeah. I think that leads into my next question, which is also how do we know when it's not working?

>> ROSENBERG: Hmm. Well, that's a good question. It depends on what illnesses we're talking about. I think when we're talking about anxiety problems, or mild depression problems, or what we call adjustment disorders, where people have a hard time adjusting to life situations, it's easier to know if it's not working because you're not getting better. If you're going to therapy for six months every week or sometimes twice a week, and it's not getting better, your symptoms aren't going away, you're not even getting better -- well, time to switch up, right?

You have to give it a shot. Sometimes you have to give it a couple sessions. Sometimes you have to give it a couple months. But you don't need to give it a couple years to see if it's working, for the most part. And it depends what therapy we're talking about. Depends what illnesses we're talking about.

But for the most part, if you have a mild psychiatric problem -- I would call mild anxiety disorder, panic disorder, depression -- you want your symptoms to go away. And with therapy and medication, they should be able to at least get diminished. If they're not getting diminished, time to move on to the next person to help you.

Now, if you have a severe mental illness, a psychotic disorder, something that really impairs your thinking, like a manic episode of a bipolar disorder, or like a psychotic episode of schizophrenia, then it's harder. Because it's very, very hard for you to evaluate anything when your mind is not working properly. That puts patients, clients, consumers, whatever you want to call them, it puts people in a -- it puts us in a very, very difficult position. Because we have to make a decision about your provider -- do we trust them? are they doing the right thing? -- when our mind might not be working properly. When we might be influenced by paranoia. Or we might even be influenced by hallucinations.

So that's a tougher question. I would say two things, if you have to evaluate your health in that situation. One is, I'd say find someone you trust. Because if you really trust them, you can hang with them, even if you don't completely agree with them. And honestly, if you knew -- if the patient knew what to do, you wouldn't even need a professional, so at the end of the day, you do have to rely on someone else's advice.

Second thing is I would trust someone else to help guide you -- parent, a child, a loved one, a best friend, a partner, whatever. I would check it out with them. But if you're a professional and your professional person you're seeing, who you've trusted in the past, and your family member or loved one or partner or best friend say, "No, you're wrong, you need

help, this is what you should be doing," I think then you kind of gotta listen to them. Especially if we're talking about those severe mental illnesses, which compromise your thinking.

It's a tough position to be in, right, isn't it? You have to try to get better while your mind is kind of all dysfunctional. That's a really hard position to be in. So you have to find people you trust who can guide you. Sort of like if you didn't have your vision, you would have to find ways to get around and folks who could tell you and help you know where you are; or find ways, as blind people do, people with any disability do -- that's really hard. My heart goes out to those folks, to evaluate that question, are they seeing the right person? At the same time, knowing that their mind is not 100%.

>> TONG: Hard to know what to trust, right? I think something that I think is really helpful for professionals to keep in mind is to connect with family members. Ideally, if there's a family member to connect with. I know there are certain situations where a person is pretty isolated. But if you can connect with family members and involve them in part of the treatment and meet with them, ideally regularly, so that it's more of a process of a family, than just as an individual. I think that goes for a lot of different treatments. But I think especially in those cases -- and especially with young children and young adults as well.

>> ROSENBERG: Yeah.

>> TONG: And I think something else that I was thinking of is just demystifying about whether we need short-term services, long-term services, and I think that's another sometimes fear of committing to therapy or mental health services: Once I see someone, does that mean I have to see them forever? And I think that's also a choice for a lot of people that you can make. I think

there are certain instances when, as you mentioned, if it's more serious, it's probably really helpful to have a long-term care team to support you. But you also have agency in your care as well.

>> ROSENBERG: Yes, so when we're talking about severe mental illnesses, for instance, people often write what's called advanced directives -- I write about this in my book -- which says if you get sick, here's what you want to happen, here's what you don't want to happen. As we were just talking about. If you become psychotic, you may not know what's best for yourself. You may not make the best decisions.

So that's sometimes it's really good to write it out, to a loved one, to a doctor, to your team, to your family, say: If I get psychotic again, here's what I want to happen. Here's what I don't want to happen. And they have some kind of direction, which they could actually present to the doctor and the medical team and say: Here's what they said when they were able to make that decision.

Yeah, you're absolutely right. People need to have agency. You need to have agency to get well. You can't just -- especially mental health treatment. You have to be a participant. You can't just be a bump on a log, and they're going to give you something, and you're going to be fine. That's not how it works.

>> TONG: Right. And I think something else that we don't always think about is the advocacy piece in mental health, in that we can advocate as professionals, as users, in building a community. So what would you recommend? I think another piece that I took away from watching your film is a sense of hope in advocacy. So I think there are pieces where, like I said,

depending on where you sit. So maybe we could start first, if you're a consumer, how can you be an advocate, whether you're a consumer or maybe a family member of a consumer?

>> ROSENBERG: There's lots of great organizations you can join. National Alliance on Mental Illness is one of many. And they advocate for legislation. And they have really great meetings where you get together. One of the ways that you can advocate for yourself is with the help of others who are in a similar situation. That gives you fellowship. That gives you support. That gives you guidance. And it gives you -- get together and help make political change.

We see in the book "Bedlam" I wrote, and in the film "Bedlam," we see how family members came together and really changed the laws in Los Angeles. I think that's really what we need. We see that in our first lady, Chirlane McCray who is Bill de Blasio's wife, who founded Thrive NYC. And really came to it from the point of view of her own experience and her daughter's experience in particular, but her own experience as well, which she talks about pretty freely. She talks about it in my book, in fact. And I think we have to take that experience that we have as patients, as family members, as consumers, and use it to change this very broken system.

>> TONG: And I think not mutually exclusive, because there's sort of overlap, but what do you feel like professionals can do, whether you're new to the field or whether you're a veteran?

>> ROSENBERG: Oh, that's a great question.

>> TONG: I feel like sometimes we are silent in some ways, because we feel like the process should be private. But I think there are pieces where we need to be really vocal.

>> ROSENBERG: Yeah, look, you have to be private about your cases. You cannot share anything about your cases. You can't get your patients to go on marches with you. There's no reason why you can't march. NAMI has a walk every year. There's lots of political action committees that people can get involved in. Everything from the right to the left.

I mean, Black Lives Matter is largely an organization which was founded for people with serious mental illness. Patrisse Cullors, who co-founded the organization, she appears in the film. She's in my book. She founded that organization because her brother -- she was afraid of her brother being beaten by the police, like so many other people with severe mental illness. I mean, 25% of fatal police shootings have to do with someone with a mental illness. So there's lots of political organizations you can get involved in.

And you don't have to go very far, you just Google that. But I think as professionals, we really have to do that. Because otherwise, you're just -- you burn out. It's a tough job. You have to feel that you're part of something moving forward, not just doing the same thing over and over again.

>> TONG: Absolutely. What have you seen, some of the advocacy efforts? What does it lead to fruition in some ways -- just to give people a picture of what could happen with advocacy?

>> ROSENBERG: Yeah, so what I write about in the book "Bedlam" is that we see that advocacy really got them to stop building a \$3 billion, 4,000-bed mental health jail, which was still a jail. It was run by the sheriffs -- a jail for people with mental illness. And divert that money towards community engagement, to community treatment.

And there's actually a wonderful judge who was just appointed as a consequence of some of this action in Los Angeles -- Judge Songhai is her name -- and I've spoken to her and spoken with her on panels several times. And basically, her job is basically to divert people out of the criminal justice system. So people with mental illness often get picked up for misdemeanors and felony crimes. As a consequence, they end up in the jail, and sometimes prison system. Her job is to divert those people to mental health courts and get those people into treatment.

So we see that. We really see some concrete change. There was a -- in 2010, Patrick Kennedy and many others in Congress passed a parity bill. Which means that if you have a mental illness, you get the same degree of care as if you had a medical illness. That's really important, because insurance companies discriminate against people with mental illness. They stop treatment. They say you only get 30 days, you only get 10 days, whatever. And now, because of that parity bill, we now have much more equitable treatment.

And what we can do when the treatment is not equitable, is under the federal government, under federal statutes, we could sue the insurance company and say you're violating the Parity Act of 2010. We've seen lots of changes, very, very good changes as a consequence of advocacy. And it's really all advocacy, frankly. It's all people demanding that there be a change. We've seen that in every disease -- cancer, HIV, that the disease course has been altered. The medical care has been vastly improved, largely as a consequence of people advocating for themselves and for their loved ones.

>> TONG: And I know you touch on this briefly in your film, but you go more in depth on a lot of these topics in your book. So I just wanted to share that with people, and I know that we have a few minutes left. I wanted to bring up something that felt very present today, which is COVID, right? We're not honoring the time if we don't think about COVID and how it's been impactful on mental health.

Something I was personally reflecting on is how when COVID first began, it was a community feeling -- we're all in this together, and we're all experiencing all these changes together. And a year in now, it's shifted where we are still having COVID change our lives, but now it's much more individualized, of how we've kind of coped with it and dealt with it, and how we're kind of functioning now. So how do you feel like one year later our society is doing mentally?

>> ROSENBERG: Well, I think that COVID has -- I think we're doing well, overall, frankly. But I think COVID has taken an incredible toll on us -- economically, socially, and probably most of all, psychologically. You know, 20%, it's estimated, of COVID cases, people who have had or have COVID, have psychological consequences as a result maybe of biological changes in the brain from the illness. Certainly the fears of COVID really messed with our brains. Our lives, our quarantined, asocial lives, lives where we had been very involved and engaged with others, now that came to a halt with COVID, and thank God, is coming to a change. Now, I think that's all had a great and terrible impact on us.

I think that the impact will be there for years to come. I think many people, especially people who experienced losses in their families, really are suffering greatly. I hope that people

will avail themselves of psychological services; deal with those losses. It's just a lot to deal with. So I think to answer your question, Stephanie, I think we're on the other side of the pandemic, but we're probably just beginning to see the neuropsychiatric and psychological ramifications of this pandemic.

>> TONG: I think one of the benefits that I've seen with COVID is just more of the acceptance, whether it's through your health insurance or people with telehealth, which has expanded services and access of services to people, and insurance companies have with co-pays and whatnot, and really try to make it much more accessible. So I think that's one benefit that I've seen through --

>> ROSENBERG: Absolutely, telehealth has really democratized mental health care. Telehealth developed years ago because there were no psychiatrists in rural communities. So if you needed a psychiatrist, you would find one through telehealth at your local emergency room, perhaps. They would connect you to a psychiatrist, maybe 500 miles away.

But I think now, everyone is doing it. I wrote a piece in the "Washington Post" not too long ago about that, that I think it really enables folks to get more care. Now, I hope the benefits -- you talk about the insurance companies lifting their limits on telehealth. I hope those benefits stay, because I think that's one of the things we've learned in COVID, that you can communicate pretty effectively, as you and I are doing right now through Zoom and through the Internet. And certainly, you can communicate that way to your patients and to your health care provider very effectively. And you don't really have to commute for 3 hours to find a good health care professional. So I hope telehealth, the benefits of telehealth, will remain.

>> TONG: Agreed. And just within our last few moments, what's next for you?

>> ROSENBERG: I'm an addiction psychiatrist with Cornell, and my main job is being an addiction psychiatrist. But we have other films that we're working on, and other books. I'm very excited and eager to share them with your audience when we're done.

>> TONG: Well, thank you so much, Dr. Rosenberg, for this time and all your valuable insights.

And we hope to speak to you very soon.

>> ROSENBERG: Thank you so much for having me.